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Between Life and Death

HIV and AIDS and Representation in South Africa

Kylie Thomas

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Abstract

This dissertation examines the relation between political and semiotic representation and takes as its focus the marginalized social position of people living with HIV and AIDS in South Africa. It argues that this position can best be understood as a space between life and death.

It engages with Michel Foucault's concept of "bio-power" to interrogate what kinds of subjects are produced when power seizes hold of life and, in particular, what becomes of subjectivity when the body is abandoned by power; and also draws on the work of cultural theorists Giorgio Agamben and Judith Butler to consider how conditions of life in South Africa in the time of HIV and AIDS both articulate with and exceed the bio-political.

The dissertation first presents a brief account of the history of the epidemic and government responses to it, and then goes on to analyse a series of visual and textual representations of people living with HIV and AIDS in Southern Africa. It does so in order to argue (Chapter Two) that representation plays a critical part in the production and preservation of what Agamben has termed "zones of abandonment".

Through readings of photographs of people living with HIV and AIDS in Southern Africa, Chapters Three and Four show how photography has become a critical site in the production of AIDS as an object of social and scientific knowledge.

Chapter Five examines the self-portraits of thirteen HIV positive women from Khayelitsha, an informal settlement just outside of Cape Town. Here, the analysis seeks to show how access to cultural representation is conditioned by the position of extreme vulnerability such women endure in the emerging social and political life of post-apartheid South Africa.

The concluding chapter compares and contrasts pre- and post-apartheid modes of mourning to show how publicly mourning those who have died of AIDS has effectively been prohibited in contemporary South Africa. The struggle, the dissertation concludes, lies not only in remembering those who have died, but in learning to recognise more fully those consigned to a spectral position somehow between life and death.

Declaration

I declare that this thesis is my own original work

Signed

Signed by candidate

Date

19 FEBRUARY 2007

In memory of

Xoliswa
Andile
Neliswa

who died of AIDS in 2002

Nompumelelo

who died of AIDS in 2003

and

Nomawethu
murdered in 2007

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Preface

Trajectory

I began to think about HIV and AIDS in South Africa in 1998. At that time I was a graduate student in the English department at the University of British Columbia in Canada, where I was working on my Master's thesis. I audited a course called "Witnessing and the Discourses of Extremity" taught by Professor Ross Chambers.¹ We read novels and poetry by and about witnesses to traumatic events; the First World War, the *Shoah*, and what Chambers terms "AIDS Witnessing". In the section of the course on bearing witness to AIDS we watched John Greyson's *Zero Patience*, read Paul Monette's elegies written for his lover, Roger Horwitz, Eric Michaels' autobiography, *Unbecoming* and Jamaica Kincaid's *My Brother*.² At the time I made a note to myself, "What is missing? Third world AIDS patients."

In the winter of 1998 I returned home to South Africa to visit my family. I travelled to stay with my aunt, Trudy Thomas, who was, at that time, Minister of Health in the Eastern Cape Province. I went with her to the opening of a clinic in rural Transkei at a place not far away from where Nelson Mandela was born. The President himself was going to be at the opening ceremony. Hundreds of people from the surrounding community gathered outside the clinic on that cold day and waited for him to arrive. When his helicopter landed the post-1994 euphoria and the presence of President Mandela made everyone forget the cold. The crowd danced and ululated; Madiba jived. Executives from Siemens were there to donate expensive medical equipment to the clinic as a birthday gift to the President. He shook their hands and thanked them because, he

¹ Ross Chambers is Distinguished Professor of French and Comparative Literature, University of Michigan. He was a visiting Professor in the Department of English at the University of British Columbia in 1998. He is the author of, among others, *Room for Maneuver: Reading (the) Oppositional (in) Narrative* (1991), *The Writing of Melancholy: Modes of Opposition in French Modernism* (1993), and *Facing It: AIDS Diaries and the Death of the Author* (1998).

² Greyson (1993), Monette (1988), Michaels (1990) Kincaid (1998).

said, they recognised that people in the third world need the best and most expensive equipment just as much as people in the first world. Then my aunt gave her speech. She thanked Madiba for asking the people at Siemens to donate equipment to the clinic, but also requested that training be provided to the clinic staff so that it would be possible for the equipment to be used. After the ceremony she introduced me to President Mandela. He asked me what I was doing and I told him that I was studying in Canada. He said, “That’s good, but you must come back home.”

At the end of 1999 I returned to South Africa and in the beginning of 2000 I went to live in rural KwaZulu Natal. I befriended several farm workers and women who were employed as domestic workers in the houses in the area. It seemed that everyone who lived there was ill; everybody was thin; everyone coughed. I attributed the ill health of my friends to their living and working conditions. I immediately set about organising for the Department of Labour to come out and give a workshop informing local workers of their rights. When I think back to that time I can hardly believe my own ignorance. Somehow, the fact that KwaZulu Natal was the epicentre of the HIV and AIDS epidemic in South Africa had completely escaped my notice. This was the year the International AIDS Conference was held in Durban, only an hour away from where I was living. Needless to say, I did not attend. Like President Mbeki, I did not see people living with HIV and AIDS. I saw extreme economic poverty, I saw racism and injustice and I saw that people were suffering. At that time I was an inhabitant of what Susan Sontag has termed, “the kingdom of the well” and I did not enter the shadowy realm of the ill, nor did I reflect too much about what it would mean to dwell there (Sontag, 1978:3). My failure to recognise the crisis of HIV and AIDS is striking in retrospect, as too is the fact that no-one ever mentioned it to me at the time. That it was possible not to think about the epidemic in a context where so many people were infected with HIV, and ill and dying of AIDS, is an indication of how acute the marginalisation of people living with HIV and AIDS was and continues to be. Just four years later I co-edited a book of poems and stories about HIV and AIDS from Southern Africa entitled, *Nobody Ever Said AIDS* (Rasebotsa et.al, 2004). The title of the collection is drawn from Eddie Maluleke's poem by the same name which so powerfully evokes the denial that plagues us in South Africa. The final stanza of her poem runs:

We all died
Coughed and died
We died of TB
That was us
Whispering it at funerals
Because Nobody Ever Said AIDS³

I have begun with this brief trajectory of how I began to think about HIV and AIDS for two reasons. One is that I wish to acknowledge the importance of the work and teaching of Ross Chambers; he offers a model to which I aspire. The other is that I wish to make clear just how little I knew about what it meant to be living with HIV and AIDS when I began this work. Becoming aware of my own blindness has led me to think quite hard about the visibility and invisibility of HIV and AIDS in South Africa and to ask a series of questions about how people living with HIV and AIDS are represented, and how this affects the ways in which they live. These questions of appearance and disappearance provide the focus for the chapters that follow, in which I explore both how people living with HIV and AIDS are represented and how they can be recognised.

These prefatory remarks are also intended to explain how I have come to write this dissertation that centres on a series of questions that can be understood as philosophical or theoretical, but that I explore in part through ethnographic methods. Before I began this dissertation I had read the work of Judith Butler and Giorgio Agamben who articulate, albeit in different ways, how “zones of abandonment” have come to characterise the present time.⁴ Their work resonated with my thinking about the place people living with HIV and AIDS occupy in post-apartheid South Africa but I could not merely assert this without learning more about the nature of that place for those who inhabit it. I wanted to understand what terms such as “the constitutive outside”, “the state of exception” and “zones of abandonment” meant for those to whom these concepts were not abstract but concrete, everyday states of being. The questions I wanted to investigate necessitated an interdisciplinary approach and meant that I rapidly became immersed in fields outside my own. As an undergraduate student at the University of

³ Maluleke in Rasebotsa et. al, (2004:20).

⁴ See Butler (1999; 2002) and Agamben (1999).

Cape Town I had majored in political philosophy, English literature and Theory of Literature. Reading theoretical and literary texts also formed the focus of my Master's degree in English at the University of British Columbia. I was interested and inspired by writings on testimony and trauma and by life narratives, however, I had never conducted interviews myself, nor had I studied anthropology, history or psychology in any kind of depth. While I might have heard of "epidemiology", I'm sure I had no idea as to what it meant.

I registered in the English Department at the University of Cape Town (UCT) for my doctorate in 2001. At the same time I began to work with Jonathan Morgan, a psychologist and writer, on a project he had just begun at UCT called the Memory Box Project. The Memory Box Project was the community outreach component of the then newly established AIDS and Society Research Unit at UCT. The aim of the project was to conduct art and narrative therapy work in communities in and around Cape Town. Both Jonathan and I had a strong interest in narrative and we both recognised the importance of documenting the stories of HIV-positive people in order to record the history of HIV and AIDS in South Africa. I wanted to conduct interviews with people living with HIV and AIDS for my dissertation and we both believed that life stories could serve as powerful advocacy tools. We began our work at a support group run by the Red Cross in Khayelitsha. The cold room in which the support group was held slowly filled up as the group members arrived: forty women, two men and twenty babies. I would never think about people living with HIV and AIDS in purely abstract terms again.

Many of the support group members were visibly ill, and those who did not appear extremely sick did not look well either. Several of the babies had terrible coughs. One man in particular seemed to be on the verge of death. He sat slumped over in his chair with a crazed expression on his face, his emaciated body in a state of collapse. At that time none of the members of the support group had access to anti-retroviral therapy. We ran Memory Box workshops in the support group and slowly learned about the lives of the group members. Several weeks passed and the very ill man we came to know as Lamla, stopped attending. Jonathan and I assumed that he would die. The following month though, he returned and looked remarkably strong. He stood in the centre of the circle of battered white plastic chairs and spoke at length in Xhosa. He seemed like a man

possessed. Afterwards we learned that he was testifying to the fact that he had started anti-retroviral therapy through *Médecins Sans Frontières* and had been returned to life. We had witnessed the seemingly miraculous power of anti-retroviral treatment right before our eyes. Jonathan and I decided to record Lamla's story and the story of his wife, Nompumelelo, also a member of the support group. This was published as "Clutching onto Hope" (Morgan et. al., 2001).

Working in that particular support group in Khayelitsha in 2001 was the most intense and difficult work I have ever done. The support group members were all unemployed and lived in shacks, most were young, single mothers of babies or small children and all were HIV-positive. In the absence of adequate health care and nutrition and in particular, without access to anti-retroviral drugs, they would all be dead within the next few years. It rapidly became clear that conducting therapy sessions and interviews with the hungry, sick support group members was an inadequate response to the crisis they were facing. I tried to hold onto the notion that it was important to document their stories in order that their struggles would be made visible. By July of 2001 six of the people I had worked with in Khayelitsha had died. Over 320 000 people died of AIDS in South Africa that year and there were approximately the same number of new infections, yet the state's refusal to provide access to anti-retroviral treatment seemed unshakeable.

At the beginning of 2002 I co-ordinated a project at the National Gallery in Cape Town which formed part of the "Positive Lives" photographic exhibition. The members of the Red Cross support group in Khayelitsha created memory boxes in the gallery space. I interviewed each participant about the images they had made and then transcribed their testimonies to display in the gallery alongside their memory boxes. The stories I recorded told of lives of struggle and despair. At that point, the chance that these people would attain access to anti-retroviral therapy seemed extremely remote and many of the participants were traumatised and depressed. The photographic images on the walls around us reflected the devastating effects of the pandemic in Southern Africa. Some of the photographs were of emaciated people dying of AIDS. While the images were powerful they were also disturbing and they elicited strong emotional responses in many of the participants in the Memory Box project. One of the members of the support group

broke down and cried after viewing the exhibition. But over the course of the two months we worked in the gallery, the space filled up with radically different depictions of people living with HIV and AIDS. Alongside the growing number of intensely colourful memory boxes was a series of images taken of people who had access to anti-retroviral treatment. South African photographer Gideon Mendel had begun to document the work of the Treatment Action Campaign and of *Médecins Sans Frontières* (MSF) in Khayelitsha. These new images were exhibited alongside Mendel's earlier works and the extreme contrast between these two sets of photographs conveyed the sense of hope that access to treatment promised.⁵

At the end of March 2002, Jonathan and I began to work in two support groups run by MSF in Khayelitsha. One of the support groups was for patients receiving anti-retroviral therapy and the other was for women who had had access to treatment during pregnancy to prevent vertical transmission from mother to child. We invited the support group members to participate in a book project to document how anti-retroviral therapy was affecting their lives. *Long Life: Positive HIV Stories* portrays the lives of thirteen women through life narratives, photographs and images they created of their own bodies.⁶ The book was the result of a year of art-making and story-telling workshops and was published at the end of 2003.⁷ Just before the book was launched, the South African government announced the adoption and details for the operational plan for comprehensive treatment and care for HIV and AIDS. The plan incorporates the provision of anti-retroviral therapy in the public health sector for South Africans with a CD4 cell count of less than 200. The importance of this shift in the government's position on HIV and AIDS cannot be overstated but, as many local doctors and AIDS activists noted, the real work of addressing the needs of people living with HIV and AIDS was only just beginning.

⁵ Gideon Mendel's photographs of people living with HIV and AIDS provide the focus for Chapter Four: "Photography and (Dis)appearance". I also discuss his work depicting people who have access to anti-retroviral therapy in Chapter One.

⁶ One man joined the project at its inception but left the group after a short time. He was the only member of the group who was employed (he ran his own vegetable stall) and did not have enough time to attend the workshops. I discuss the significance of the central place women's bodies have been made to hold in the discourse surrounding HIV and AIDS in South Africa in Chapter Five.

⁷ See Morgan, Jonathan and the Bambanani Women's Group, (2003). Jane Solomons facilitated the art making process and Kali van der Merwe designed the book.

Although the South African government began to provide anti-retroviral therapy in the public health sector in the beginning of 2004, the stories of the women I worked with in Khayelitsha remain the exception rather than the rule. In 2004 over 360 000 people in South Africa died of AIDS. According to the Treatment Action Campaign, of the approximately 500 000 people who require anti-retroviral therapy in South Africa, only 50 000 are receiving treatment.⁸ People living with HIV and AIDS in South Africa continue to occupy a place between death and the law, a place I articulate here in theoretical terms as the borderlands of the bio-political state.

⁸

See www.tac.org

Introduction

Bio-political Borderlands

In the borderlands
you are the battleground

Gloria Anzaldua⁹

In a chapter entitled “Fear of Touching” in his fascinating study of the relation between the body and the city, *Flesh and Stone*, Richard Sennett writes of the segregation of the Jews in mediaeval Venice. Sennett terms the three ghettos that were created between 1516 and 1633 to house the Jews, “urban condom[s]”. “When the third Ghetto [the Ghetto Nuovissimo, opened in 1633] was filled with people” he writes, “the population densities were about triple those of Venice as a whole” (Sennett, 1994:236).

Because of these physical conditions, plague found a welcome home in the Ghetto. The Jews sought to protect themselves by recourse to their own doctors, but medical knowledge could not combat the condition of soil and buildings, as well as the ever-mounting density of population. When plague struck in the Ghetto, the gates of the Ghetto were instead locked for most of the day as well as night. (Sennett, 1994:236)

Sennett connects the devastating effects of the plague to the ways in which the city of Venice was divided so as to form spaces of social and political inclusion and exclusion. Sennett’s identifies the plague in the Jewish Ghetto as a disease of racism. His metaphor of the Ghetto as a “prophylactic space”, resonates with the ways in which the HIV and AIDS epidemic is spatialised in the world we inhabit today, both locally, where it is largely confined to the spaces occupied by the poorest members of society, and globally, where the highest numbers of people living with HIV and dying of AIDS are situated in

⁹ Anzaldua, (1987:194).

the third world; 26,6 million of the 40 million people infected with HIV live in Sub-Saharan Africa, nearly half of these in Southern Africa alone.¹⁰

Thinking about the ways in which the epidemic is spatialised draws attention to the politics of visibility and invisibility that have played a central part in how the epidemic has unfolded in different places across the world. This dissertation was written in the shadow of Table Mountain, the stony heart around which the suburbs and townships of the city of Cape Town are located. The mountain was incorporated by the architects of apartheid to fundamentally organise the spatial and social geography of this place, the general principle being that the further away you are from the mountain the more marginal your place in the life of the city. While much has changed in post-apartheid South Africa, the geography of segregation remains largely intact. This spatial divide is a telling signifier of the continuities between the inequalities of the present and the past.

When I began working on my thesis in 2001 I also began to work on the Memory Box Project and together with Jonathan Morgan, I ran art and narrative therapy workshops in support groups at clinics and hospitals in many of the informal settlements that surround the city. From the middle of 2001, and for the next year, we were to work in Khayelitsha, a black African township on the Cape Flats, almost exclusively.¹¹ At least three times each week we travelled from the university, situated on the slopes of Table Mountain, to the township, leaving the affluence and comfort of the spaces we occupied in the city behind us. Of the 400 000 people thought to be living in Khayelitsha at that time, 40 000 were estimated to be HIV-positive.¹²

The divide between the material conditions of life in the township and of life outside it is extreme – while there are exceptions, the majority of those who live there are struggling to survive.¹³ The conditions of life of those who live outside the bounds of the city are, for the most part, invisible to those who dwell within the city-limits. Movement between the spaces of the city and the townships is economically prohibitive for many

¹⁰ UNAIDS Sub-Saharan Africa Epidemiological factsheet (www.unaids.org).

¹¹ For a fascinating account of the history of Khayelitsha, see Cook (1986).

¹² See Goemaere (2002). There are now an estimated one million people living in Khayelitsha.

¹³ “I Eat with Robbed Money”, an article in the weekly South African newspaper the *Mail and Guardian*, shows how extreme violence and poverty characterise conditions of life in Khayelitsha today. See Joubert (2007).

township-dwellers. Having arrived in the township many people never attain the means to travel out again, either to return to the rural places they left behind or even to simply journey into the city or surrounding suburbs. It also remains uncommon for white people to travel outside of white spaces and into black or coloured areas; most white Capetonians travel past these vast shack-lands at high speed, on their way to the airport or to the winelands situated not far beyond the townships. The majority of people living with HIV and AIDS in South Africa dwell in high-density, economically impoverished spaces like Khayelitsha. The failure of the state and of South African society more broadly to adequately respond to the crisis of the HIV and AIDS epidemic is connected to this spatial divide that is at one and the same time both economic and psychic.

During the time I worked in Khayelitsha, *Médecins Sans Frontières* (MSF) were beginning to provide treatment for people living with HIV and AIDS. I saw how, once people were receiving treatment, they were returned to health. I also saw that there were many more sick people than the clinic could provide for and that, in spite of the critical intervention MSF was making in unambiguously showing that anti-retroviral therapy could be effectively administered in resource-poor settings, many people did not have access to treatment and, as a result, were dying. On each of my return journeys to the city from the township I would travel towards the mountain, which resembled more and more a vast tombstone, its blind face a metaphor for the myopia of the residents of the city. I imagined a commission being established to restore to the dead their proper names, to undertake to inscribe them in stone, across the face of the mountain, incontrovertible evidence of their lives, their deaths.

As my desire to simply make visible the lives of people living with HIV and AIDS attests, I began this project with the rather naïve idea that if people living with HIV and AIDS could tell their stories, if they could only be heard, they would be recognised as subjects of and by the law. I suppose I imagined that their socio-economic struggles would simply fall away once they gained entry into the realm of representation, both political and semiotic. I soon came to see that the problem lay less in whether people living with HIV and AIDS were represented than in *how* they were represented. I came to understand that the entry of people living with HIV and AIDS into the realm of representation could, and often does, only serve to compound their desubjectivisation.

Like Eric Michaels, the author of the brilliantly titled memoir of living with and dying of AIDS, *Unbecoming*, I have sought to show how being named HIV-positive often interpellates a particular kind of subject, one that enters into representation only to be unmade as a subject (Michaels, 1990). I have come to understand representation itself as a problem, one that is bound both to recognition and to loss. It is this problem that forms the central focus of this work.

The Problem of AIDS and Representation

AIDS is not, and has never been, merely a medico-scientific object. It has always been at once also a social, political, economic, historical, philosophical and literary object. Which means that AIDS was not, either logically or chronologically, first of all a medico-scientific object that somehow then became an object for other knowledges. This is perhaps obvious but it bears emphasis because it implies – necessarily I think – not merely that AIDS, as object and in its objectness, is discursively constituted (a commonplace in many quarters) but also that “it” does not exist in some primordial ontological viral plenitude, only subsequently subject to the disciplines of knowing.

William Haver¹⁴

When I first began my dissertation my working title read as follows: “Writing HIV/AIDS: Towards a Living History in Post-Apartheid South Africa”. At that time my primary focus lay in listening to and documenting the stories of people living with HIV and AIDS, analyses of which I thought would constitute most of the content of this dissertation. In 2002 I even transferred to the Department of Historical Studies, to work with Sean Field, an oral historian and director of the Centre for Popular Memory. Between 2001 and 2003, I interviewed approximately 50 people living with HIV and AIDS in the Western Cape. A small number were people I had worked with intensively over time, creating memory boxes, books and self-portraits. I developed relationships with them and interviewed them at length. Others were people I hardly knew at all, members of the Red Cross Support group in Khayelitsha who participated in the Memory

¹⁴ Haver, (1996:4).

Box Project at the National Gallery in Cape Town in 2002 and who I worked with closely over just a short period of time. The effect of bearing witness to their words and to the testimony of their bodies provides the motivating force of this dissertation. But my role as historian of the epidemic was rather short-lived.

In August 2002 I left Cape Town and Khayelitsha to take up a position as a visiting scholar at the University of California at Berkeley. My advisers there, Judith Butler in the Department of Rhetoric and Film, and Lawrence Cohen, in Medical Anthropology, helped me to formulate a critical approach to the work I had been doing in South Africa. When I returned home in 2003, John Higgins, Professor of English at UCT, agreed to be my primary supervisor. Jane Bennett, at the African Gender Institute at UCT, was my co-supervisor and an important interlocutor from the start. Conversations with her served to remind me of how testimony cannot be thought outside of relations of power and led me to reflect on my own position in relation to those whose stories I heard. The more I thought about the problem of representation, the less possible it seemed for me to engage in representing those whose life narratives I had recorded.

When I reflected on the testimonies I had heard, the questions that engaged me were more properly philosophical than historical in nature. I began to think about testimony as a problem rather than as a privileged site of access to the “truth” of the subject, and to consider how representation is connected to subjectivity, recognition and erasure. Rather than writing a history of the epidemic, I have been concerned with the question “How does the history of the epidemic come to be written?” How do we represent it and how do we read those representations? How are people living with HIV and AIDS constituted through those representations and what are the ways in which they have contested them? What conditions the entry of the HIV-positive subject into the realm of representation? In the chapters that follow I explore how representation operates as a field of transformation and contest where the political and cultural are continually reconfigured. Through readings of textual and visual representations of people living with HIV and AIDS, I examine the paradoxical way in which the appearance of the body with AIDS at the same time results in the disappearance of the subject of that body.

Chapter One, “The New Apartheid: HIV and AIDS in South Africa”, provides a description of the history of HIV and AIDS in South Africa, focusing specifically on the

ways in which the epidemic has been represented. I argue that demands for particular kinds of productive and reproductive bodies have shaped the responses to the epidemic of both the apartheid and post-apartheid state. The disciplinary power of the apartheid state seized hold of bodies; those defined as white citizen-subjects and those cast as black non-subjects. The state's fanatical circumscription and control of the movements, interactions and intimacy of black South Africans and between different racial groups was accompanied by the creation of vast zones of abandonment. Within these limbo spaces black South Africans were made to occupy a place between life and death, subject to the law and yet unrecognised as subjects with rights. Among these spaces were the so-called "homelands", the townships and the mine-compounds, the backyard rooms of domestic servants, a myriad of spaces of "social death".¹⁵ I consider how in the post-apartheid context, and primarily because of the ways in which people living with HIV and AIDS have been "abandoned" by the state, such spaces have not disappeared but have assumed new forms.

In a lecture delivered at a colloquium at the University of Cape Town in November 2006, Judge Edwin Cameron called for the establishment of "an AIDS TRC" to allow the experiences of people living with HIV and AIDS to be publicly recognised and for the state's failings in dealing with the epidemic to be laid bare.¹⁶ Besides the shadow of the mountain, this dissertation has been written in the shadow of the Truth and Reconciliation Commission and the discourses that have proliferated around it. The powerful discourses that have shaped the post-apartheid body politic – discourses of healing from the wounds of the past, of reconciliation and of the "African Renaissance" – are chronically incommensurable with the experiences of the majority of South Africans living with HIV and AIDS. The marginalised position of people living with HIV and AIDS in South Africa cannot be disconnected from their marginalisation within the narrative of South African history and new-nation building. In the first chapter I argue for the epidemic to be understood as continuous with, rather than distinct from, the larger

¹⁵ I draw the term "social death" from Orlando Patterson's *Slavery and Social Death* (1982). I discuss this concept in greater depth in Chapter Two.

¹⁶ Edwin Cameron is a Judge in the South African Supreme Court of Appeal. He founded and was the first director of the AIDS Law Project in Johannesburg and is one of the most visible public figures openly living with HIV in South Africa. His autobiographical memoir *Witness to AIDS*, is both a compelling personal account of living with HIV and AIDS and an excellent history of the epidemic in South Africa. See Cameron (2005).

history of South Africa. While I have not undertaken an examination of the connections and continuities between those who testified at the victim hearings at the TRC and the life-narratives of people living with HIV and AIDS post-apartheid here, I think that these accounts can be productively read through and with one another.

It is important to link the experiences of people living with HIV and AIDS now with conditions of life under apartheid for at least two reasons. In the first place making these connections explicit prohibits the past from being put behind us, as if apartheid could be reduced to a kind of anti-foundation myth against which “the new South Africa” constitutes itself. Instead it demands that we attend to the ways in which we are foundering against that past, all its remnants made visible through our cities, our hospitals, our bodies, our “child-headed households”, our affluence, our rapists, our invisible provinces populated by the starving and the sick, our epidemic, and through all that divides us still.

Secondly, recognising that the spread of the epidemic in South Africa and even in Southern Africa more broadly can be linked to what might be termed “apartheid fallout”, is to recognise that addressing social inequality in the region means addressing the needs of people living with HIV and AIDS just as much as the needs of anybody else. Writing of the Ukraine in the aftermath of the Chernobyl disaster, Adriana Petryna describes the perverse economy in which diagnosis as a “sufferer” with radiation sickness became a desirable condition. She writes that:

...these citizens’ experiences expose the existence of patterns that ought to be traced in other post-socialist contexts: the role of science in legitimating democratic institutions; increasingly limited access to health care and welfare as the capitalist trends take over; and the uneasy correlation of human rights with biological self-preservation. (Petryna, 2003:7)

While there are significant differences between post-apartheid South Africa and the post-socialist states, Petryna’s analysis of the position of “sufferers” in the Ukraine and their struggle for recognition by the state in an emerging neo-liberal democracy, has striking parallels with the position of economically impoverished South Africans living with HIV and AIDS. For people living with HIV and AIDS without access to the medical treatment and care they require, the euphoria of South Africa’s transition to democracy was short-lived. In post-apartheid South Africa, as in post-socialist Ukraine, juridical rights have

been extended to all citizens and yet in each state, “a large and largely impoverished segment of the population has learned to negotiate the terms of its economic and social inclusion in the most rudimentary life-and-death terms” (2003:7). Petryna shows how being recognised as a citizen by the state hinges on attaining what she terms, “biological citizenship.”

The second chapter, “Between Bio-politics and Social Death: HIV and AIDS and the limits of ‘the human’”, argues that the struggle to gain access to treatment for people living with HIV and AIDS in South Africa has been a struggle for precisely such recognition. I argue that up until November 2003 when the state announced that it would begin to provide free anti-retroviral therapy in the public health system, people living with HIV and AIDS in South Africa occupied a place between life and death, a position that is both literal and metaphoric. Since the rollout of treatment began approximately 200 000 people have begun to take anti-retroviral drugs. According to the Treatment Action Campaign, however, this is only a fraction of those who require such treatment. The majority of people living with HIV and AIDS continue to dwell in spaces I term here “bio-political borderlands”.¹⁷

The first chapter begins by analysing the case of an HIV-positive woman who was “lost” in a state hospital to argue that the systemic neglect of people living with HIV and AIDS within the public health care system in South Africa is a form of social death. In order to elucidate this state of being “between life and death”, the second chapter draws on Orlando Patterson’s concept of “social death” which he employs in his analysis of the desubjectivisation of slaves in *Slavery and Social Death* (Patterson, 1982). I then turn to an analysis of the work of Giorgio Agamben in particular the argument that he makes in *Homo Sacer: Sovereign Power and Bare Life*, that the state of exception has become the law (Agamben, 1998). I then consider how the concept of social death and the concept of bare life can be employed in order to understand the position of people living with HIV and AIDS in present-day South Africa. I consider how people living with HIV and AIDS in South Africa have been cast as abject, their lives not recognised as lives.

¹⁷ On the rollout of anti-retroviral therapy and the state of the national treatment programme see Hassan (2005).

Social death can entail being cast out of one's home, abandoned by one's family and friends and lovers, and being excluded from participation in one's community. Social death also refers to being abandoned by power, to be cast out of the realms within which one is recognised as a subject of the state, a citizen, and to be denied the rights afforded to those considered citizen-subjects. I argue that the manifestation of this state of being that is at the same time a state of non-being in contemporary South Africa can best be understood in relation to what Michel Foucault has termed "bio-power" and the "bio-political".

In the final section of *The History of Sexuality Volume One* and in *Society Must Be Defended*, a collection of his lectures at the College de France published in English in 2003, Foucault traces the emergence of "bio-politics", a new form of state power, one that has usurped the place of sovereign power and that, he argues, increasingly determines conditions of life in the contemporary global order. Chapter Two draws on Foucault's work to interrogate what kinds of subjects are produced when power seizes hold of life and in particular, what becomes of subjectivity when the body is abandoned by power. Like Ulrike Kistner, I argue that bio-power has not replaced sovereign power but that these two forms of power co-exist in an uneasy relation (Kistner, 2003). Sovereign power, the power to take life and let live, comes to be entangled with bio-power, the power to make live and let die. The position of people living with HIV and AIDS indicates how conditions of life in South Africa both articulate with and exceed Foucault's conception of bio-power.

The Problem of Testimony, Mourning and Loss

Over the course of the six years that I have been working in this field and immersed in thinking about the epidemic and the experiences of people living with HIV and AIDS, I have been struck by how invisible this crisis remains. In spite of the remarkable work of the Treatment Action Campaign and allied organisations campaigning for the rights of people living with HIV and AIDS, such as MSF and the AIDS Law Project, the lives, struggles and deaths of so very many people in South Africa continue to go unmarked in

the public domain. In this dissertation I argue that the powerful discourses that have shaped how we think about HIV and AIDS have meant that suffering, grief and death have largely been disavowed. Prohibited from openly mourning the deaths of those we know, as well as all those we do not, we have come to occupy a state not of melancholia but of something closer to catatonia, a state in which we cannot recognise the lives of people living with HIV and AIDS, let alone begin to grieve for their deaths. In the chapters that follow I seek to draw connections between political and semiotic representation and between recognition and mourning.

Chapters Three and Four focus on readings of several photographic images of people living with HIV and AIDS in Africa in order to show how appearance can at the same time be a form of disappearance. The analysis there draws on the writings of two influential theorists of photographic representation, Roland Barthes and Susan Sontag. The third chapter, “Violent Imaginings: Representation, Africa and AIDS”, argues that contemporary images of AIDS in Africa intersect with a long history of colonial representation within which the continent is cast as a space of death. Through an analysis of two series of photographic images, one from a special issue of *Time* magazine on AIDS in Africa “Death Stalks A Continent” (2001) and the other from Dutch journalists Geert van Kesteren and Arthur van Amerongen’s *Mwendanjangula! AIDS in Zambia* (2000), I examine how AIDS in Africa has entered the global imaginary through the discursive construction of “African AIDS”.

In Chapter Four, “Photography and (Dis)appearance”, I show how narrative has increasingly come to be attached to photographic images that represent people living with HIV and AIDS in Africa as a way to secure their claim to be representing the truth of the subjects they portray. This chapter focuses on the work of Gideon Mendel, a South African-born photographer whose body of work provides the most significant photographic record of the effects of the epidemic in Sub-Saharan Africa. In his recent work documenting the struggle for access to treatment in South Africa, Mendel uses narrative extensively. I read this shift in his practice as connected to a wider cultural turn towards testimony as a privileged mode of access to the “truth” of the subject.

Chapter Five examines what it means to dwell within zones of abandonment through close readings of the portraits made by thirteen HIV-positive South African

women of their own bodies. These portraits were produced through a series of workshops held over the course of a year as part of a collaborative project between *Médecins Sans Frontières* in Khayelitsha, the Bambanani Women's Group, and the Memory Box Project. I engage in close readings of these portraits and also reflect on the project and its contested afterlife. My analysis draws on Gayatri Spivak's "Can the Subaltern Speak?" to problematise the relation between testimony and the transparency of the subject, and to argue that for socially and economically marginalised HIV-positive black women, access to representation is a critical yet troubling concern (Spivak, 1993).

Chapter Six, "Mourning the Present", the concluding chapter, raises the question of what is at stake in failing to recognise the enormity of the losses of HIV and AIDS. I interrogate the ways in which personal experiences of HIV and AIDS have been made unspeakable and I argue for spaces of public mourning. I draw on Judith Butler's work on mourning and her articulation of "publicly ungrievable losses" in *Antigone's Claim* (2000) and in *Precarious Life* (2004) to think about how those who have died of AIDS enter, and are erased from, public memory in South Africa.

I juxtapose two instances of loss in South Africa in times of mass death. The first is drawn from *The Diary of Maria Tholo*, a chronicle of life in the townships outside of Cape Town in 1976 when the schoolchildren rose up against the apartheid state; the second is Sindiwe Magona's "Leave-Taking", a story of multiple losses in the time of AIDS. I argue that to grieve the losses of AIDS is also to grieve for the losses of apartheid. This profound state of mourning is one that has been foreclosed by the prohibitions placed on mourning by the apartheid state, by the process for confronting the injustices of apartheid carefully circumscribed by the TRC, and by the post-apartheid state's disavowal of the losses of the present.

I then read Diane Victor's evocative "Smoke Portraits", a series of portraits of people living with HIV and AIDS in the Eastern Cape. These images are made from ash and cannot be preserved over time. Unlike the photographic medium which is bound up with the desire to hold life and fix time, Victor's haunting portraits insist on the importance of bearing witness even as they testify to the impossibility of the monumental. Her work suggests that recognising the losses of AIDS implies recognising our own fragile embodiment.

The chapter concludes by reflecting on the effects of the prohibitions placed on mourning the losses of AIDS through the narrative of Pindiwe, an HIV-positive woman I interviewed in 2002. Her narrative is a stark portrayal of how being positioned outside of community is to be exposed to death, both metaphoric and literal.

Community between life and death

In her book *Borderlands/ La Frontera*, Gloria Anzaldua describes the border between the United States and Mexico as:

una herida abierta where the Third World grates up against the first and bleeds. And before a scab forms it haemorrhages again, the lifeblood of two worlds merging to form a third country – a border culture. Borders are set up to define the places that are safe and unsafe, to distinguish *us* from *them*. A border is a dividing line, a narrow strip along a steep edge. A borderland is a vague and undetermined place created by the emotional residue of an unnatural boundary. It is in a constant state of transition. The prohibited and forbidden are its inhabitants. (Anzaldua, 1987:3)

Anzaldua's words draw attention to how the border space, in spite of being set up in order to keep things apart, is itself a space of crossing, of mixing, of transition. The borderland points to the uncertainty and ambiguity that haunts all attempts to categorise, separate, and distinguish "us from them". The borderland as a space of possibility and transgression is perhaps a utopian view of such spaces, a way in which to understand how something productive might emerge even in the face of the dehumanising divides. For as I show here, the borderland provides a vivid metaphor to describe the marginalised position of people living with HIV and AIDS in South Africa.

It is interesting to note how theorists who have sought to describe the condition of social death employ metaphors of space rather than subjectivity – Etienne Balibar's "death-zones", for instance, as opposed to "communities of the living dead".¹⁸ And presumably this is so because to be "living dead" is to be outside of, beyond, community. Indeed, I argue here that to be positioned outside of the social and political is to be unmade as a subject and that the production of "zones of abandonment" can be

¹⁸ Etienne Balibar cited in Kistner (2003)

understood as the unmaking of community. And yet, if within these zones so much is broken down, there are also new forms of solidarity, community and kinship that are being forged. If the death zone is the new world order, thinking through the impossible possibility of community between life and death is a critical task.

Two weeks ago, Nomawethu Ngalimani, a woman I would call my friend if that were not to disavow all that made real friendship possible between us, was stabbed to death in her home in Khayelitsha. Nomawethu's self-portrait is hanging in the Constitutional court, a sign of her symbolic inclusion in the body of the nation. A memorial service was held for her a week after she died. I found myself unable, unwilling, to attend. I wanted to participate in collectively grieving for her death but I did not want to go to the house in which she had been murdered. My own sense of vulnerability to the violence of this place and time, made more acute in the aftermath of Nomawethu's murder, immobilized me. I try to tell myself that I am mourning for her in my own way. At the same time, all that keeps me from expressing my grief in community is what I rail against here.

In this moment, as in many others over the time I have been writing this, the daily injustices faced by those who occupy what Giorgio Agamben terms "zones of abandonment", have been made painfully clear. To be writing criticism in such a time feels, as Ross Chambers so eloquently puts it, "like getting on with one's needlework while the house burns down" (Chambers, 1998:vii). In his meditation on writing and AIDS, at the same time a reflection on what it means to engage in literary criticism, Chambers suggests that the work of the critic can be understood as a work of mourning. His suggestive analysis of the relation between reading, recognition and mourning has provided a way for me to hold onto the significance, however slight, of this work. It is as a work of recognition and of mourning that I hope this dissertation will be read.

Chapter One

“The New Apartheid”: HIV and AIDS in South Africa¹⁹

In *Infections and Inequalities: The Modern Plagues*, anthropologist and physician Paul Farmer argues that the deaths of many millions of people in the world today who die of diseases that can be treated is a sign of “how fundamentally social forces and processes come to be embodied as biological events” (1999:14). The position of people living with HIV and AIDS is one that he articulates in the following way:

Increasingly, what people with AIDS share are not personal or psychological attributes. They do not share culture or language or a certain racial identity. They do not share sexual preference or an absolute income bracket. What they share, rather, is a social position – the bottom rung of the ladder in inequalitarian societies. (Farmer, 1999:91)

His incisive analysis of the contemporary global order through which he “trace[s] the march of inequality [...] through the bodies of the poor” (1999:280), emerges from his work as a medical practitioner in rural Haiti where he has borne witness for two decades to what he terms “biological expressions of social inequality” (Farmer (1999:262).²⁰ Farmer’s conception of the relation between biological infection and social inequality offers a compelling approach to understanding HIV and AIDS in South Africa.

The way the epidemic has unfolded in South Africa makes evident the marginalisation of people living with HIV and AIDS, both under apartheid and in the new democratic dispensation. I begin this chapter with an analysis of an account by Ncedeka, an HIV-positive woman I interviewed in Khayelitsha in 2002. Her narrative provides a particularly vivid instance of the position of people occupied by people living

¹⁹ Archbishop Desmond Tutu refers to HIV and AIDS in South Africa as “the new apartheid” in his preface to *Waiting to Happen: AIDS in South Africa* (2004).

²⁰ See also anthropologist Didier Fassin’s formulation of HIV and AIDS in South Africa as “embodied history” (Fassin, 2002).

with HIV and AIDS in contemporary South Africa – a position between life and death, as “citizens without rights”.²¹

In the second section of the chapter I show how Ncedeka’s “social death” as a person living with HIV and AIDS is by no means arbitrary. I argue that the policies of the apartheid state laid the ground for the crisis we are facing today, and then turn to an analysis of how the response of the post-apartheid government has exacerbated this crisis. I also describe the emergence of the highly visible HIV and AIDS activist movement in South Africa, and, specifically, the Treatment Action Campaign. In conclusion I discuss a series of portraits by photographer Gideon Mendel that document how access to anti-retroviral therapy has affected the lives of people living with HIV and AIDS.

Between Life and Death

When I met her, Ncedeka was a member of the anti-retroviral therapy support group at *Médecins Sans Frontières* in Khayelitsha. She chose to participate in the Long Life Book Project and I interviewed her in Khayelitsha in July 2002.²² What follows is her account of what occurred when she arrived in Cape Town from the Eastern Cape in 1999 and was admitted to a state hospital on the verge of death. Ncedeka was transferred to a different hospital without her mother’s knowledge and was effectively lost for an entire month. Her story is evocative of how people living with HIV and AIDS have been “disappeared” by the health-care system, within which, prior to the provision of treatment, they were cast as the “living dead”.

For the first month, for the first month, I stay the whole month not seeing my mother, not seeing anyone. My mother, the day I was transferred from Brooklyn to, from Jooste to Brooklyn, the doctor transferred me there, then my mother go there to look for me. Then the doctor wasn’t there. Then the nurses who were there, they said, “no, we don’t know where she is.” Then my mother said, “no, she was lying there in that bed so why can’t you tell me if she is dead or what?” They said, “no, we don’t know.” She said, “OK, I am going to call the police so they are going to investigate what happened to my child.” So they said to her, “we just quickly going

²¹ Balibar cited in Kistner (2003)

²² I write about Ncedeka’s self-portrait she painted as part of the Long Life Book project in Chapter Five, where I also include additional information about her story.

to look from the phone books and we are going to phone there those hospitals.” Then they phoned and phoned and phoned. Then they found me in Brooklyn. Then even in Brooklyn, when my mother go there to visit me, when she was on the gate you see you have to sign. When the patient get inside the hospital the driver of the ambulance have to sign down if how many patients and their names. But when they looked on the book, there was no name Ncedeka here, there. So my mother as she described that she is looking like this, so the other security says, “no, I have an idea. Just go to check in that ward.” So she found me there. Lucky. But if that security didn’t tell her she was supposed to go back without finding me. So I don’t know what was going to happen to me.²³

Ncedeka provides an account of a time in which she is extremely ill and is struggling to hold onto her physical life and yet her description has less to do with her physical pain than it concerns the tenuous hold she has on her subjectivity. In relating the events of her own disappearance Ncedeka confronts the possibility of her own death: both her physical death and the death of her self as subject. Ncedeka states that if her mother had not found her, “I don’t know what was going to happen to me.” Ncedeka’s narration of a time in which she was lost (to others and, as I will show, to herself) illustrates how we depend on recognition in order to be: if we are to be recognised as subjects we must appear to and for others. Ncedeka is transferred from one hospital to another and for a month she does not see anyone she knows. When Ncedeka’s mother goes to the hospital to find her no-one can inform her how to find her daughter. Ncedeka’s disappearance leads her mother to wonder whether or not her daughter is dead. At first the nurses say that they, like Ncedeka’s mother, do not know whether she is alive or not.

Ncedeka then relates how she was “found” in a different hospital but when her mother goes there to look for her, she discovers that her daughter’s name has not been inscribed in the admittance register. The absence of her name could be attributed to administrative oversight; in the context of HIV and AIDS in South Africa, however, the absence of Ncedeka’s name is a striking reminder of her position as non-subject. Having a name is crucial for representation in the political sphere – one always acts *in* the name of something and *with* the name that permits recognition. Our names may prohibit entry or grant us access to particular spheres of sociality and it is through our names that

²³ Interview with Ncedeka, 2002.

we are made recognisable to others.²⁴ Having a name binds us to the self that is that name and signifies our belonging to a family, a culture, a nation. Without a name we are sundered from the sphere of sociality – even a name I do not want might serve to secure me a place within the realm of the social and political and might come to be the grounds for my resistance to and subversion of that name.²⁵

In *AIDS and the National Body*, cultural theorist Thomas Yingling articulates how the construction of HIV and AIDS as an object of knowledge has been attended by the desubjectivisation of the person living with HIV and AIDS. He writes that in the absence of adequate intervention from the state, activist groups in Britain and the United States created their own prevention and awareness campaigns and “attempted to wrest from dominant culture the wholly negative if not annihilative representation of HIV infection and AIDS, and to construct in its stead a discourse of empowerment, meaning, and possibility” (Yingling, 1994:101). He argues that central to this work was the assertion of the subjectivity of people living with HIV and AIDS:

But more than the politics of desire is at stake in thinking about AIDS: in fact, it may well be that AIDS has said more about identity in our culture than it could ever say about desire. More specifically, we might ask – through Lacan and others – about the mirror stage and the relation of the “I” to its body, for we encounter in living with AIDS the production of non-subjects, people for whom the mirroring illusions of discourse are broken: the host body in this case continually reminds its subject – with every glance in the mirror – of the distance between the “I” and its lesions, and of the fact that the lesions may not be subsumed into any transcendence; thus, one of the most important discursive moves from the beginning has been the insistence on the designation “person with AIDS.” (Yingling, 1997:15-16)

The designation “person living with HIV and AIDS” has been claimed by AIDS activist groups globally and in South Africa by organisations such as the National Association of People Living with HIV and AIDS, and the Treatment Action Campaign which issues t-shirts to its members imprinted with the words “HIV-positive”. Yet as Yingling observes, “we encounter in living with AIDS the production of non-subjects” and the name of the person designated “person with AIDS” is all too often subsumed by the name of AIDS

²⁴ In the following chapters I return to the significance of naming and recognition in relation to media representations and the desubjectivisation of people with living with HIV and AIDS in Africa.

²⁵ See Judith Butler’s analysis of the political import of providing names for the dead in her *Precarious Life* (2004).

and its endless negations. The designation “person with AIDS” is both a coming into being and what is, in writer Eric Michael’s term for the unmaking of AIDS, simultaneously “Unbecoming”. The emergence of the category of being “person living with HIV and AIDS” has been turned against those it names to effect the disappearance of that category of being.

Once named HIV-positive, the subject is marked for death and, expelled from the sphere of communality, the person first endures a social death and then physically dies of AIDS. This applies particularly in South Africa, where the state has denied its HIV-positive citizens access to life-saving medication. Before November 2003 when the state announced it would begin to provide anti-retroviral therapy in the public health sector, once a sick person was diagnosed HIV-positive they were discharged from the hospital and left to die in the passageways, in a hospice, or in their homes²⁶. Regardless of how ill a patient was, they could receive only palliative care as the provision of anti-retroviral therapy in the public health system was forbidden by law. While a National Treatment Programme is now in place in South Africa, the majority of people living with HIV and AIDS still do not have access to such treatment.

Ncedeka did not die in hospital, her mother describes her physical appearance to a security guard at the hospital and he suggests that Ncedeka may be in one of the wards. Mother and daughter are reunited and Ncedeka survives to narrate her own disappearance that comes to serve, paradoxically, as the grounds for her appearance within discourse. Ncedeka becomes recognisable to herself as she speaks the story of her life and incorporates her experience of being lost to her self within that narrative. In narrating her experience she also becomes recognisable to others who bear witness to her account.

Although Ncedeka has lived through her own social death, her uncertainty about what would have happened to her had her mother not found her remains. While Ncedeka is returned to herself and to others through language, her return carries with it a reminder of the silences of the dead. Her story is one that carries the stories of those who were dying and could not return. Ncedeka’s testimony, both the condition and the articulation

²⁶ I base these claims on my own observations in public health facilities in the Western Cape between 2001 and 2003 and on conversations with Dr Joanna Taylor about conditions in public hospitals in Gauteng and Mpumalanga and Dr Trudy Thomas about the state of the public health system in the Eastern Cape and KwaZulu Natal. See also Gibson (2001).

of her return from death, exhumes the silences of those who died unrecognised. In this way her testimony enacts an impossibility; her words return the dead from death to haunt the living and to speak their demands.

Ncedeka's testimony can be read as an indictment of the South African health system in which the bodies of patients can be lost without trace. Yet to read her experience only as a sign of the failure of the health system is to fail to recognise her as a subject. Her words indicate how the appearance of a body with AIDS inaugurates the disappearance of the subject of that body and that if people living with HIV and AIDS are to be recognised as subjects both the questions that are posed and the answers that are given about HIV and AIDS in South Africa need to be reformulated. Instead of asking, "what can Ncedeka tell us about the failings of the health system?" the question I want to raise here is: "what do the failings of the health system tell us about Ncedeka and the position she occupies in relation to the nation-state?" In the section that follows I begin to address this question through a brief account of the history of the epidemic in South Africa. Ncedeka's marginalisation cannot be understood without a consideration of how the epidemic has unfolded in relation to the political struggle at the end of apartheid and the formation of the new South African state.

HIV and AIDS in South Africa

The first two cases of AIDS in South Africa were reported in 1982. For the next eight years, HIV infection rates were highest among white gay men.²⁷ While the state was aware that large numbers of men in the gay community were infected and that the epidemic was likely to spread to the broader community, the first official HIV and AIDS campaigns in South Africa did little to raise awareness or prevent further infections. As in many other places, homophobia, racism and sexism determined medical, state and civil society responses to the epidemic. In many ways it was not surprising that the government never implemented a coherent and effective plan to prevent the spread of

²⁷ Webb, (1997:23)

HIV: the apartheid state condemned homosexuality and treated black South Africans as sub-human.

In 1985, when the first deaths from AIDS occurred in South Africa, the migrant labour system was at its peak – 1 833 636 South Africans were classed as migrants and half a million workers were employed on the goldmines.²⁸ The migrant labour system was one of the causes of the rapid spread of HIV in South Africa in the early stages of the epidemic and migrant mineworkers were among the first heterosexual men to test positive for HIV in large numbers in South Africa.²⁹ Conditions of life for migrant labourers were extremely harsh; they worked for little pay, lived in single-sex hostels and were separated from their families and communities for long periods of time. As T. Dunbar Moodie has documented, sexuality and masculinity were reconfigured on the mines.³⁰ Homosexual relationships, often between an experienced miner and a younger newcomer to the mine, were common and were known as the taking of “mine wives”. These relationships offered intimacy, sexual pleasure and a kind of apprenticeship in harsh conditions.³¹ Men on the mines also engaged in sexual relationships with women who lived in the surrounding towns and with female sex-workers. The effects of the migrant labour system on sexual practices and family structures were, and continue to be, wide reaching and have led to high HIV-prevalence rates across both urban and rural parts of South Africa.³²

The formation of the “Bantu Homelands” was an integral part of the migrant labour system in South Africa. The “homelands”, largely set up on existing reserves in

²⁸ Whiteside and Sunter (2002:63)

²⁹ See Campbell (2004)

³⁰ Dunbar Moodie (1994). See also Breckenridge (1998) and Harries (1990). Zackie Achmat offers a critique of accounts of male-to-male sex that fail to acknowledge same-sex desire in his “ ‘Apostles of Civilized Vice’: ‘Immoral Practices’ and ‘Unnatural Vice’ in South African Prisons and Compounds, 1890-1920” (1993).

³¹ Both Dunbar Moodie and Campbell report a decline in homosexual relationships on the mines since the 1970s. Although conditions on the mines have improved since the end of apartheid, miners continue to live in single-sex hostels and are separated from their families for long periods of time. It remains common for miners to have multiple sexual partners.

³² As Whiteside and Sunter note, HIV-prevalence rates are similar in rural and urban areas in South Africa while in African countries to the north, rural areas tend to have lower prevalence rates (2000:53). Large numbers of workers from other countries in Southern Africa also formed part of the mobile labour force in South Africa. Botswana, Lesotho, Swaziland, Mozambique and Zimbabwe all have extremely high HIV-prevalence rates (see UNAIDS epidemiological country surveys, www.unaids.org).

the least hospitable parts of the country, were intended to divide Africans “into distinct ‘nations’ based on their ‘historic homelands’” (Worden, 1994:111). As Nigel Worden puts it in his excellent survey of South Africa’s modern history, “Ethnic homeland loyalty was to replace national political aspirations in a move which the state hoped would defuse calls for the moral necessity of African self-government within South Africa itself” (Worden 1994:111). The creation of the “homelands” effectively rendered all black South Africans stateless: “homeland” citizenship was imposed on all Africans in 1970 and the “homelands” were granted nominal independence from South Africa over the course of the next ten years. “By this process,” Worden writes, “citizens of the ‘independent’ homelands lost their South African nationality, although the homelands were not recognised as independent by any other country” (ibid).

Workers ordinarily returned from their places of work in the urban centres to their families in the rural “homelands” twice a year. Conditions of life in the “homelands” were very difficult and as rural poverty increased, more and more people sought employment in the urban centres. Able-bodied adult men were usually absent for long periods of time and the burden of providing for their families fell on women. In her paper “Migrancy and HIV/AIDS”, Simonne Horwitz writes that the migrant labour system also affected sexual practices in the rural areas where women increasingly resorted to sex with multiple partners in exchange for subsistence:

Absent husbands who got involved in relationships in the city often did not fulfil their promise of sending remittances back to the rural areas. During the nineteenth century an abandoned woman could expect to be taken in by her kin but as the kinship system began to break down, she had to look elsewhere. With the high rate of unemployment and the way in which gender relations were constructed, one of the few options available to these women was to become involved in relationships of sex in exchange for money and very often food and care. The most likely partner would be an unattached returning migrant – given that he would have some money to support her. (Horwitz, 2001:11)

Under apartheid black women faced severe hardship and constituted the most economically impoverished and socially marginalised sector of the population. In post-apartheid South Africa many women now also have the superadded burden of HIV infection with which to contend.

Women in South Africa are particularly vulnerable to infection with HIV – both physically and socially – because of the unequal relations of power that exist between men and women, and because they continue to be economically marginalised. Young women are increasingly engaging in cross-generational sex with men who are able to offer financial compensation in the form of school fees, clothing, food and cell-phones.³³ The prevalence rates of HIV infection in young women in South Africa make the gendered nature of the epidemic painfully clear – for every two infected 15-24 year old males in South Africa, there are five infected females of the same age.³⁴

In their paper drawing on successive field studies conducted by teams of anthropologists with women in informal settlements and rural areas outside of Durban in KwaZulu Natal, Ida Susser and Zena Stein observe that, “the greatest risk of infection in the areas we studied is faced by young women, probably those in the 15- to 25-year-old age group” (2004:134). During the course of their research conducted to explore levels of awareness about HIV and AIDS and women’s agency, Eleanor Preston-Whyte and Ida Susser attended a meeting with a group of women living in an informal settlement and found that while the women knew that condoms could prevent the transmission of HIV, none of their partners used condoms. The women articulated their economic dependency on men as one of the primary factors that placed them at risk of HIV infection: “‘Poverty makes prostitutes of us,’ they said” (Susser and Stein, 2004:137).³⁵

In May of 2004 the National Youth Survey found that 77% of young South Africans infected with HIV are women. The survey found infection rates to be highest around informal settlements where levels of unemployment, poverty and violence are high, and young people are often left alone without parental guidance and care.³⁶ In 1995 teenage pregnancies accounted for one-third of all live births in South Africa and 31% of girls reported that they had dropped out of school because of unplanned pregnancies.

In her study on women and constitutional change in post-apartheid South Africa, Hannah Britton writes:

³³ See Hunter (2002) and Campbell (2000)

³⁴ According to the Medical Research Council and the Centre for Actuarial Research, 14% of young people in South Africa between the ages of 15 and 24 are HIV-positive. The prevalence rate for young men is 5.8% while for young women it is almost four times that at 21.6%.

³⁵ See also Wojcicki (2002)

³⁶ In 1993 an estimated seven million people were living in informal settlements around the major cities and towns. This figure has increased rapidly since the end of apartheid.

Life for the majority of South African women continues to be marked by socio-economic hardships, patriarchal domination, and frequent gender violence. South Africa continues to lead the world in terms of violence against women and was from 1996-7 the nation with the highest reported incidents of rape. (Britton, 2002: 44)

South Africa continues to have the highest incidence of rape in the world and since 1996, 20 000 incidents of child rape have been reported each year. Police crime statistics for the period January to December indicate that 13540 children under 17 years were raped. Of these children, 7899 were younger than eleven years old. These figures are almost certainly lower than the actual number of rapes that occurred due to the fact that sexual abuse is often not reported.³⁷ It is difficult, if not impossible for women to negotiate safer sexual practices, such as the use of condoms, with their male partners in a context where rape and other forms of physical violence against women are commonplace and are used as a form of punishment.³⁸

During the negotiated transition to democracy, a coalition of 90 women's groups lobbied for the rights of women to be recognised by the new Constitution and to have fair representation in the new state structures. As a result, almost one third of all parliamentarians in South Africa's first post-apartheid government were women and the new Constitution enshrined women's rights. While the struggle for women's equality has been successful in both the legislative and institutional sense, this has not been sufficient to bring about structural change in the public and private spheres. Britton argues that "one of the root causes of women's continued inequality may be found within the inadequate reform models used during the anti-apartheid movement" (2002: 44). She claims that:

As national leaders are beginning to recognize, the models did not disrupt the public/private, male/female dichotomies or transform existing state institutions, which privilege male discourse and power. For women's liberation to be complete,

³⁷ See Jewkes and Abrahams (2002). In January 2002 a scandal erupted when doctors in a hospital in Kimberley in the Northern Cape defied government regulations and used anti-retroviral therapy to treat a nine-month-old baby who had been raped and sodomized. Media reports about sexual violence against children have highlighted the need for post-exposure prophylaxis to prevent the transmission of HIV after rape.

³⁸ See for instance the cases of Gugu Dlamini and Mpho Motloutse who were murdered for disclosing their HIV positive status and of Lorna Mlofane who was raped and murdered after she told her rapists she was HIV positive. I include further information about these cases in Chapter Five.

the nation will need to go beyond legislative revision and focus on altering societal structures. (Britton, 2002:44)

The precarious place women continue to occupy within the emerging social order highlights the disjuncture that exists between the promises set out in the Constitution and conditions of life in contemporary South Africa. The question of how rights guaranteed by the Constitution can be secured for all South African citizens is a crucial one, since at present the majority of the population falls through the cracks of constitutional reform. Developing a clearer understanding of how it has been possible for citizens to hold civil rights, but at the same time be effectively positioned outside of the protections of the state, remains a critical task.

State Responses to the Epidemic: Apartheid and After

In 1987 the South African government declared AIDS a communicable disease and proposed quarantine as a solution to the growing HIV and AIDS epidemic in South Africa.³⁹ The right of the state to quarantine HIV-positive people was passed into legislation and although quarantine was never carried out, the state's draconian approach to HIV and AIDS was made clear.⁴⁰ Rather than HIV and AIDS being understood as a threat to the health of individuals, HIV-positive individuals were identified as a threat to the body politic. Anxieties about threats to the integrity of the national body through miscegenation had shaped South African politics and society from the colonial era. The ideology of apartheid worked through generating fears in the white population about the need to protect their racial purity and to guard against the threat of contamination. The right-wing was quick to associate the risk of HIV infection with the threat of racial contamination and "claimed that AIDS was synonymous with returning ANC cadres trained in countries further north, particularly Zambia" (Webb, 1997:74).

From the start the semiotic dimension of the epidemic was badly understood but everywhere apparent. In 1985 the apartheid government's Department of Health launched

³⁹ *HIV and AIDS in Africa*, 1997:74.

⁴⁰ Niehaus notes that in 1987 nine people in South African prisons were found to be HIV-positive people and two people had AIDS. They were placed in isolation. See Niehaus, 2001:22.

its first HIV and AIDS awareness and prevention campaign. Instead of conveying clear information about the means of transmission of HIV and how to avoid infection, the campaign made use of an image of coffins in graves. The campaign that followed depicted skeletons as the bed partners of sexually active couples, which, as Webb notes, only served to create further confusion in the minds of South Africans (1997:74). In the context of 1980s South Africa, images of death, particularly those featured in a government campaign, were associated with political violence.⁴¹ Even if the links between sexual practices, HIV infection, AIDS, illness and death had been made apparent, black South Africans certainly had reason to doubt and fear the motives of the state in its attempts to control their sexual behaviour. Webb notes the use of Depo-Provera contraceptive injections as a form of “population control” in Namibia and Whiteside and Sunter state that at the Truth and Reconciliation hearings it emerged that HIV was used as a weapon by the apartheid state when HIV-positive askaris were instructed to infect sex workers (Webb, 1997:74; Whiteside and Sunter, 2000:65).

The next government HIV and AIDS awareness campaign was launched in the early 1990s and was known as the “yellow hand campaign”. Its logo was the outline of a yellow hand against a black background accompanied by the slogan, “AIDS: Don’t Let It Happen”. While the design was presumably intended to reach member of all racial groups within South Africa, many black South Africans, and domestic workers in particular, read the yellow hand as a symbol of the protective gloves used for domestic tasks by white “madams” in their homes. Under apartheid white spaces were imagined as pure and construed as always being under threat of contamination by the presence of black servants. At the same time, black workers were often responsible for the running of white households and for the care of white children and would often live in servant’s quarters on the properties of their employers. The image of the yellow hand fed into the paranoia of white South Africans and as Webb observes, was dismissed by many black people as propaganda by the state (Webb, 1997:75).

As in many countries in Africa and other previously colonised parts of the world, HIV and AIDS awareness and prevention campaigns in South Africa have been met with

⁴¹ Webb cites Van Niftrik who writes of the campaign depicting coffins in graves, “the general perception seemed to be that the scene portrayed victims of political violence” (Webb, 1997:73).

deep suspicion. In his study on HIV and AIDS in Haiti entitled *AIDS and Accusation: Haiti and the Geography of Blame*, Paul Farmer maps out how, like the rhetoric of “African AIDS” within which Africa is conceived as the fount of infectious disease, the discursive construction of Haiti as the origin of AIDS exposes the inherent racism of early medical and popular understandings of the epidemic (Farmer, 1992). He notes that such conceptions led to the emergence of “countertheories to explain both the origin and the rapid spread of AIDS” as stigmatised Haitians and Africans responded to the accusations levelled against them (1992:227).

The most common of these was the assertion that the virus causing AIDS had been created wilfully, in a United States military laboratory. This theory was equally popular in sub-Saharan Africa. ‘One of the main attractions of the theory is undoubtedly that it blames the United States for AIDS. It has appeared repeatedly in Third World newspapers, by authors who view the U.S. debate over the possible origins of AIDS as evidence of racism and a determination to blame Africans’. (Sabatier 1988, cited in Farmer, 1992:228).

Scepticism about HIV and AIDS in South Africa is certainly a legacy of the policies of the apartheid state, but confusion about the epidemic has been fuelled by the response of the post-apartheid government. In her paper, “South Africa: Touched by the Vengeance of AIDS”, Mary Crewe argues that the state and non-governmental organisations have failed “to persuade a sceptical population that AIDS is a real disease and not some part of some other more devious agenda” (Crewe, 2000:23). Confusion and denial about HIV and AIDS in South Africa has been generated, in large part, by public statements made by President Thabo Mbeki and other high-ranking government officials who have contested whether HIV causes AIDS and the efficacy of anti-retroviral therapy.⁴² Mbeki has disputed the link between HIV and AIDS and has claimed that HIV and AIDS statistics are exaggerated.⁴³ He argues that the racism of the west and of white South Africans leads them to read African sexuality, particularly male sexuality, as out of

⁴² In this section I focus on President Mbeki’s public statements about HIV and AIDS. The Minister of Health, Manto Tshabalala Msimang, has made similar statements. Both Parks Mankahlana, who was Mbeki’s Presidential spokesperson, and Peter Mokaba, long-time leader of the ANC youth league, held dissident views and, although the state denied it, both were said to have died of AIDS.

⁴³ See “Mbeki Questions Spending on AIDS” in *Business Day*, 10 September 2001. See also Mbeki’s address to African National Congress MPs, 28 September 2000, as cited in the *Mail and Guardian*, 6 October 2000: “Mbeki said that if one agreed that HIV caused AIDS, it followed that the condition has to be treated by drugs and those drugs were produced by the big western drug companies. The drug companies therefore needed HIV to cause AIDS, so they promoted the thesis that HIV caused AIDS, he said.”

control and as a source of disease.⁴⁴ HIV and AIDS policies have indeed been shaped by racist discourses and practices and this may account for some of the suspicion Mbeki holds towards mainstream scientific opinion. In February of 2000 the South African government set up the “Presidential International Panel of Scientists on HIV/AIDS in Africa”, which included several AIDS dissidents, to determine whether HIV causes AIDS and whether anti-retrovirals (in particular the drug AZT) were toxic. In his letter to world leaders in April 2000, excerpts of which were published in the South African newspaper the *Sunday Times* in an article titled “Reciting Comfortable Catechisms on AIDS is not Good Enough” Mbeki calls for an African solution to “this uniquely African catastrophe”:

It is obvious that whatever lessons we have to and may draw from the West about the grave issue of HIV/AIDS, a simple imposition of Western experience on African reality would be absurd and illogical. [...] I am convinced that our urgent task is to respond to the threat that faces us as Africans. We will not eschew this obligation in favour of the comfort of the recitation of a catechism that may very well be a correct response to the specific manifestations of AIDS in the West. We will not, ourselves, condemn our own people to death by giving up the search for specific and targeted responses to the specifically African incidence of HIV/AIDS. (Mbeki, 23 April 2000)

Yet, as Mary Crewe observes, in response to the formation of the Presidential Panel on AIDS, it is ironic that “in an attempt to find an ‘African response’ to AIDS, outside experts are called in and local experiences ignored” (Crewe, 2000:24). The state’s choice to focus on the views of dissident AIDS researchers has led to a great deal of controversy. An early attempt on the part of the state to find a local solution to HIV and AIDS led the government to support research into a new drug called “Virodene”, which its promoters claimed offered a possible cure for AIDS, this in spite of the fact that the drug had not been tested in clinical trials. In 1997 the Virodene scandal erupted in South Africa when the Medicines Control Council reported that it had found the primary ingredient of Virodene to be a toxic industrial solvent used in the plastics industry, unsafe for human use. In his letter Mbeki defends the right to debate dissenting views in the

⁴⁴ See Mbeki’s address at the Inaugural ZK Matthews Memorial Lecture, University of Fort Hare, 12 October 2001: “Convinced that we are natural-born, promiscuous carriers of germs, unique in the world, they proclaim that our continent is doomed to an inevitable mortal end because of our unconquerable devotion to the sin of lust.” See also “Letter from the President” in *ANC Today* regarding the incidence of rape in South Africa.

post-apartheid context and goes as far as to accuse those who call on him to cease consulting with dissident scientists of practising apartheid style censorship:

Not long ago, in our own country, people were killed, tortured, imprisoned and prohibited from being quoted in private and public because the established authority believed that their views were dangerous and discredited. We are now being asked to do precisely the same thing that the racist apartheid tyranny we opposed did, because, it is said, there exists a scientific view that is supported by the majority, against which dissent is prohibited. (Mbeki, 23 April 2000)

By 2000, the relationship between the government, the medical profession and activists was reaching boiling point. In July 2000 the International AIDS conference was held in Durban and scientists from all over the world signed the Durban Declaration, stating that HIV is indisputably the cause of AIDS and that anti-retroviral therapy is an effective form of treatment. In his address at the opening session of the conference, Mbeki stated, "Some in our common world consider the questions that I and the rest of our government have raised around the HIV/AIDS issue as akin to grave criminal and genocidal conduct. What I hear repeatedly, stridently, is, 'Don't ask questions'" (Mbeki, 2000:6) While the President defended his own right to question mainstream scientific views, those who questioned what, if anything, the state was going to do for the five million South Africans living with HIV, were cast as racist afro-pessimists, unable to see anything but a bleak future for the new South Africa. In a letter to Tony Leon, leader of the opposition party, the Democratic Alliance, Mbeki writes:

I imagine that all manufacturers of antiretroviral drugs pay great attention to the very false figures about the incidence of rape in our country, that are regularly peddled by those who seem so determined to project a negative image of our country. The hysterical estimates of the incidence of HIV in our country and sub-Saharan Africa made by some international organisations, coupled with the earlier wild and insulting claims about the African and Haitian origins of HIV, powerfully reinforce these dangerous and firmly-entrenched prejudices. None of this bodes well for a rational discussion of HIV/AIDS and an effective response to this matter, including the use of anti-retroviral drugs. (Mbeki, *Sunday Times*, 9 July 2000).

The desire to deconstruct the negative stereotypes that determine how Africa is seen and treated in the global political order runs through Mbeki's public statements. The vision of South Africa, and indeed of the whole African continent, that Mbeki foresees is a space

of hope and renewal.⁴⁵ This conception of the body politic requires a particular kind of citizen-subject whose embodiment reflects the health and wholeness of the nation-state. As I hope to make clear in the chapters that follow in this dissertation, the bodies of people living with HIV and AIDS are chronically incommensurable with such a conception of the body politic and, as such, find no place in the new social order.

In South Africa, as Hein Marais observes, the rise in HIV-infection rates coincided with a time of extreme political instability:

By the early 1990s South Africa was the only country in the world which had to contend with an exponential rise in HIV prevalence rates in the context of a major political transition. In 1990-1994, therefore, what was unavailable was the institutional and political stability – not to mention the political legitimacy of the government – necessary to implement a coherent and co-ordinated response. (Marais, 2000:6)

The post-apartheid state's attempts to respond to the growing crisis have clearly been over-determined by the legacy of apartheid. At the same time the epidemic has been exacerbated by the policies of the government which have been characterised by denial and a seemingly callous indifference to the ceaseless suffering and death of so many of its citizens.

In his address at the International AIDS Conference in Durban in 2000, Nelson Mandela made oblique reference to the denialist position of the African National Congress government, and Thabo Mbeki in particular, when he called on government leaders to take action against HIV and AIDS: "In the face of the grave threat posed by HIV/AIDS, we have to rise above our differences and combine our efforts to save our people. History will judge us harshly if we fail to do so now, and right now." A few months later Mbeki informed the ANC that he was withdrawing from the public debate about the science of HIV and AIDS. While the President may no longer have been airing his views in public, he clearly was no closer to accepting the efficacy and necessity of anti-retroviral therapy for people living with HIV and AIDS.

In the section that follows I focus on the emergence of the HIV and AIDS activist movement in South Africa and the strategies of resistance that have been employed in response to the policies of the state.

⁴⁵ On the concept of the African Renaissance in South African political rhetoric see Maseko and Vale (2002).

Resistance

Archbishop Desmond Tutu has referred to HIV and AIDS as “the new apartheid” as the struggle for access to treatment and for the right to life has replaced the struggle against racial oppression.

The end of apartheid was a historic and momentous moment in the life of South Africa. But our suffering has not ended. Just as we were bringing to a close a terrible chapter in our history, another crisis was just beginning. [...] We have five million citizens who are HIV positive. We have already lost well over a million of our brothers and sisters to AIDS. We have over 600 000 AIDS orphans. And the end of this plague is still not in sight; the worst still lies ahead of us. (Tutu, 2004)

In 1998 a social movement called the Treatment Action Campaign was formed in South Africa to campaign for the rights of people living with HIV and AIDS to access to treatment and care. The Treatment Action Campaign is both a continuation of the mass democratic movements formed during the struggle against apartheid and a new kind of social movement born out of the post-apartheid present where citizens are in competition for scarce resources. The Treatment Action Campaign (TAC) has drawn on the history of protest in South Africa in their awareness and resistance campaigns, but in significant ways TAC has followed a different path to resistance movements under apartheid. This is primarily because TAC has had recourse to the transformed justice system and has used legal expertise to secure a number of important victories against the state. From its inception TAC began to call on the state to develop and implement a comprehensive national treatment plan for people living with HIV and AIDS.

TAC's first campaign centred on the highly emotive issue of the provision of treatment for pregnant women in the public health care sector to prevent the transmission of HIV from mother to child. The results of the Bangkok perinatal AZT study, published in 1998, “indicated that a short-course regimen with the anti-retroviral drug Zidovudine (also known as AZT) during the last four weeks of pregnancy has the potential of decreasing the transmission from mother-to-child by 51%” (www.tac.org). In 1999, Dr Nkosasana Zuma, then Minister of Health, stated that she supported TAC's call to make

AZT accessible to pregnant women in the public health sector but that the high cost of the drugs made the rollout of treatment impossible. In the same year, a study conducted by the Medical Research Council estimated the total cost of the programme to prevent mother-to-child transmission would be R16 054 million – less than one percent of the national health budget. “The study concludes that a national programme to reduce mother-to-child transmission of HIV infection in SA would be an affordable, cost-effective and potentially cost-saving public health intervention” (www.tac.org).

In July 1999 the results of the HIVnet 012 study conducted in Uganda showed that the anti-retroviral drug Nevirapine demonstrated similar results to AZT and was more cost-effective and easier to administer. With the support of the South African government, TAC called on pharmaceutical companies to lower the price of essential medicines. In particular, TAC began a campaign calling on pharmaceutical giant Glaxo-Wellcome to lower the cost of AZT. Then in October 1999 President Mbeki addressed the National Council of Provinces and asserted that there was evidence to suggest that AZT was a toxic substance. While prior to this time the state had argued that it could not provide anti-retroviral therapy for economic reasons, Mbeki now justified the state’s position by arguing that such treatment represented a risk to the health of the nation. In a report in the *Cape Argus* Mbeki is cited as saying, “There also exists a large volume of scientific literature alleging among other things, the toxicity of this drug is such that it is in fact a danger to health”.⁴⁶

In the beginning of 2000 TAC took legal action to ascertain the government’s position on the prevention of mother-to-child transmission of HIV. The Legal Resource Centre and the AIDS Law Project took on the case and argued that pregnant women had a constitutional right to reproductive health care. In August 2001 TAC’s court case against the government began.⁴⁷ The Pretoria High Court ruled in TAC’s favour and ordered the state to provide Nevirapine as a matter of urgency. The government elected to appeal the decision in the Constitutional Court. At the same time as the state was contesting the decision of the High Court that they should be responsible for providing medication to prevent vertical transmission, the Congress of South African Trade Unions called on the

⁴⁶ See Sawyer (1999). See also Wakin (1999).

⁴⁷ See Deane (2001) and Beresford (2001).

government to declare HIV and AIDS a national emergency. Access to treatment for people living with HIV and AIDS was proving to be an extremely divisive issue in South African politics.⁴⁸

In March 2002 the provincial government of KwaZulu Natal, the province with the highest rates of HIV infection in the country, defied the National Department of Health and began to supply Nevirapine to all pregnant women who wished to take it.⁴⁹ Shortly afterwards the Constitutional Court ruled that the state had a constitutional duty to provide Nevirapine to prevent vertical transmission of HIV. 18 pilot sites for the prevention of mother-to-child transmission were set up in clinics across the country. At this time 26.5% of women attending antenatal clinics in South Africa tested HIV-positive.

In 2001 TAC used the iconic image of the body of Hector Peterson, a 14-year-old boy shot dead by the police during the 1976 student uprisings in Soweto, in one of their posters. The image of Peterson's dead body and of his grief-stricken sister running alongside the boy who carries his body is instantly recognisable in South Africa as a signifier of the injustice of the apartheid state and the necessity for struggle against oppression. TAC juxtaposed this image with a photograph of Nkosi Johnson, the 12-year-old AIDS activist who spoke at the International AIDS Conference in Durban in 2000 and called on leaders to recognise the plight of children living with HIV and AIDS. Johnson died in May 2001. The juxtaposition of these highly emotive images overtly linked the struggle against HIV and AIDS with the struggle against apartheid. In March 2003 TAC laid charges of culpable homicide against the Minister of Health, Manto Tshabalala Msimang, and Minister for Trade and Industry, Alec Erwin. At the time more than 600 South Africans were dying of AIDS-related diseases every day. Like ACT UP in the United States in the 1990s, TAC has played a crucial role in asserting the presence of people living with HIV and AIDS in a context of silence and shame.

On the 19 November 2003 the government announced the Operational Plan for Comprehensive Treatment and Care for HIV and AIDS; a national treatment plan that

⁴⁸ The Trade Unions played a central role in the struggle against apartheid and have enormous popular support. The African National Congress, the South African Communist Party and COSATU formed an alliance before the first democratic elections in 1994. The government's neo-liberal economic policies and stance on HIV and AIDS have created a serious rift in the tripartite alliance.

⁴⁹ See Beresford (2002).

included the provision of anti-retroviral therapy for South Africans living with HIV and AIDS with a CD4 cell count under 200. The government promised that, “within a year there would be at least one [anti-retroviral] service point in every health district across the country, and within five years, one service point in every local municipality.” In February 2004 the Minister of Health claimed that the state was still evaluating the health services before the Department of Health could begin dispensing drugs. Each clinic or hospital where anti-retrovirals would be distributed had to be accredited by the Department of Health. By March 2004 only 13 sites had been accredited, all of these in the Western Cape Province.

Access to anti-retroviral drugs significantly affects how people experience their condition – AIDS is no longer understood as a death sentence but as a chronic manageable illness, just as it is for people living with HIV and AIDS in the west. In Chapters Four and Five I draw attention to how access to anti-retroviral therapy has also affected how people living with HIV and AIDS are seen and how they see themselves. I argue that the campaign for access to treatment has led to a marked shift in the ways in which people living with HIV and AIDS are represented. In Chapter Four I analyse the photographs of Gideon Mendel, a South African born photojournalist who has been documenting HIV and AIDS in Southern Africa since 1999. In 2002 Mendel created a series of images of people who, like the women I worked with in Khayelitsha and whose self-portraits I analyse in Chapter Five, were among the first in South Africa to gain access to anti-retroviral therapy through *Médecins Sans Frontières*.

Mendel’s photographs of people who have access to anti-retroviral therapy provide a striking counter-point to his earlier work, which I analyse in Chapter Four. In contrast to the black and white images of sick and dying people I read in that chapter, Mendel’s use of testimony and colour in his later work, as well as the participation of those depicted in determining how they are represented, contribute to the sense that those depicted are people living with HIV rather than dying of AIDS (Mendel, 2002). And indeed, as people who have access to anti-retroviral therapy, the lives and stories of those who feature in Mendel’s more recent work are markedly different from those who do not. Their sense of being among the chosen few emerges through their testimonies, which appear alongside their images and many of which valorise both TAC and MSF. Each

person's narrative recounts their experience of being extremely ill and being returned to life from the brink of death once they began to take anti-retroviral drugs. What is striking about these accounts is how well versed each person is about both the medical aspects of their condition and the contested terrain of treatment access in South Africa. One of the images is a portrait of Nontsikelo Zwedala, a young woman who has access to treatment for three years through a clinical trial. She states:

I believe the government should provide treatment for everybody. Thabo Mbeki should know that HIV causes AIDS, and it is killing people. He should know that it can be treated to allow people to live a long life with HIV. He must not stick on the resistance and side effects only. If he cannot afford to buy the treatment from the pharmaceutical companies he must talk to them to lower their prices because I know their prices are much too high now. There are options like generic producing and parallel importing. He can reduce military spending because there is no war in South Africa but people are dying of AIDS. (Mendel, 2002:24)

Zwedala, like many of those who had access to anti-retroviral therapy prior to the inception of the state anti-retroviral programme, is a member of TAC. In South Africa in 2002 where so few people living with HIV and AIDS had access to the treatment and care they required, beginning to take anti-retroviral drugs and becoming an activist were often related processes. This arose because of the highly politicised debate about access to treatment in South Africa that left people living with HIV and AIDS no option but to campaign for their rights to be recognised, and as a result of the close association between MSF and TAC. The existence of TAC has led to the formation of coherent activist identities that powerfully counter stereotypical perceptions of people living with HIV and AIDS.

The pervasiveness of a sense of the importance in raising awareness about the effectiveness of anti-retroviral therapy for people who do have access to treatment is made clear through Mendel's portrait of a man who has not publicly disclosed his HIV-positive status. The image shows his outstretched arm with his drug-adherence sheet in his hand and is accompanied by his narrative that intersects with the rhetoric of HIV and AIDS activism in South Africa. He states, "I choose to show my daily drug-adherence sheet, which I have to fill in every time I take my medication. People must know that a poor person like me living in a shack can take these drugs properly. They are my chance

to live.” His narrative demonstrates his knowledge of his condition and his familiarity with anti-retroviral drug regimens:

Tygerberg referred me to MSF here in Khayelitsha and they started looking after me with anti-retrovirals. At that point my CD4 count was 38. I had full-blown AIDS; my viral load was 1,2 million. I was given AZT and 3TC with nevirapine but I began getting a blood problem so I was changed from AZT to ddI with d4T and Efavirenz. This combination is working for me now. My weight then was very low. It was 38kg; but now it is 57kg. I had a lot of memory loss but my memory has come back. My viral load is now undetectable and I will get my new CD4 count results next week. These drugs have made a huge difference in my life. (Mendel, 2002:25)

As I argue in the following chapter, access to anti-retroviral therapy in South Africa today in the public health sector marks the entry of people living with HIV and AIDS into the political sphere and signifies a form of recognition by the bio-political state. At the time the testimonies above were recorded however, people living with HIV and AIDS occupied a place between life and death, what I describe here as “bio-political borderlands”. The 177 people who were receiving anti-retroviral therapy through MSF in Khayelitsha in 2002 were granted a secure hold on their physical life, but their claim to civic “life” continued to go unrecognised. Even now, three years since the rollout of treatment in the public health sector began, the majority of people living with HIV and AIDS continue to occupy a precarious place on the margins of the emerging social order. Many South Africans who require anti-retrovirals have not yet gained access to treatment and many continue to face stigma and discrimination. Often the combination of the failings of the health care system and the widespread stigma people living with HIV and AIDS experience intersect. Many sick people only seek treatment when they are on the verge of death or they fail to seek treatment at all. Throughout this dissertation I argue that the forms of social death to which people living with HIV and AIDS have been made subject, like those described by Ncedeka in the account with which I began this chapter, are intimately bound to their physical deaths, and specifically, how and when they die.

In the following chapter I argue that differential access to healthcare in South Africa marks the emergence of bio-political borderlands, spaces between life and death. Biological citizenship can be understood as a way of negotiating this “space between”, of staking a claim to citizenship precisely through those characteristics which previously

served as the grounds for exclusion from the socio-political. Becoming a “biological citizen” – gaining access to social grants, medical care, and recognition by the state – in South Africa today is fraught with difficulty. The socio-economic conditions of life of many people living with HIV and AIDS, the forms of violence to which they are made subject, and the social death many people continue to endure, mark the continued existence of zones of abandonment.

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Chapter Two

Between Bio-politics and Social Death: HIV and AIDS and the limits of “the human”

In Chapter One I described the experience of Ncedeka, an HIV-positive woman who inhabits what I have termed the “bio-political borderlands” of the post-apartheid state. The chapter engages with the theoretical writings of Michel Foucault, Orlando Patterson and Giorgio Agamben to examine the relation between bio-politics, social death and the production of “zones of abandonment”. While these theorists do not refer specifically to South Africa their work provides a way to understand the contemporary global social order of which South Africa increasingly forms part.

The relation between the subject and power is mediated in democratic political contexts by human and socio-economic rights which provide a code for, and place limits on, how power might be exercised.⁵⁰ It is through the discourse of rights and the notion of “the right to have rights” that the citizen-subject is constituted. In post-apartheid South Africa human rights have been central in the formation of the new nation-state and in conceptualisations of a new body politic, one that includes all South Africans as citizens.⁵¹ The South African Constitution, adopted in 1996, has been lauded as the most liberal in the world. However, the disjuncture between the vision of the Constitution and the social and economic conditions of the majority of people living in South Africa remains the central challenge of and for the post-apartheid state.

The position of people living with HIV and AIDS in South Africa has brought into sharp focus how rights on paper do not always translate into lived experience. In this chapter I consider how the response to the HIV and AIDS epidemic at state level has raised a series of questions about how one comes to be constituted as a subject and

⁵⁰ See Michael Ignatieff’s Tanner Lectures *Human Rights as Politics and Idolatry* (Ignatieff, 2001) and Wendy Brown’s incisive response (Brown, 2004).

⁵¹ See Govender (2006:94).

recognised as such, and what it means to be denied that recognition. I begin this chapter with the question of rights and how rights, in as much as they apply predominantly to living persons, can be understood as an instrument of what Michel Foucault has termed “bio-politics”, the form of modern state power that seizes hold not only of individual bodies but of “man-as-species”, of the population, of life itself. I then turn to Foucault’s articulation of “bio-power” and “bio-politics” in *The History of Sexuality Volume One* and in the series of lectures he delivered at the College de France in 1976, *Society Must be Defended*, published in English in 2003. Like anthropologist Adriana Petryna, for whom Foucault’s articulation of “bio-power” provides a way to think through conditions of life in post-socialist, post-Chernobyl Ukraine and a theoretical formulation to think *against*, I argue here that Foucault’s diagnosis of the workings of modern state power provides an extremely useful way to think about forms of power and conditions of life in contemporary South Africa.

The HIV and AIDS epidemic casts light on how the expansion of bio-power in South Africa is concomitant with the production of spaces of social death. While Foucault argues that such spaces of exclusion do not fall outside of the logic of modern state power but are a component of it, his own work does not explore this dark underside of the bio-political. In order to think about what it means to inhabit what I describe here as “bio-political borderlands”, the spaces occupied by the majority of people living with HIV and AIDS in South Africa, I draw a connection between Foucault’s work and the work of theorists who have sought to understand the condition of “social death”. I point to how there has been a fundamental split between those who argue that bio-politics is the new global order (Paul Rabinow, Nikolas Rose) and those, like Ulrike Kistner, who claim, along with philosopher Giorgio Agamben, that the state of exception has become the law.⁵² I argue that the HIV and AIDS epidemic in South Africa casts light on how these two seemingly opposing theorisations of modern state power can be seen to be working in tandem. I argue that the position of people living with HIV and AIDS in

⁵² On bio-power see Rabinow and Rose (2003); Petryna (2002) and Bashford (2006). On the persistence of sovereign power see Agamben (1998) and Kistner (2003). See also Žižek for his thoughts on bio-politics, democracy and a pointed critique of what he terms “the fashionable notion of ‘multitude’” (2004:514). See Norris (2000) for a close analysis of Agamben’s work.

South Africa is a precarious one, located in the interstices between biological citizenship and the non-being of social death.

A Question of Rights

“You can’t be going around having promiscuous sex and hope that you won’t be affected by something or other.” Mbeki said it was not the government’s responsibility to compel individuals to behave in a specific way. But people could not behave as they wished and then, when they fell ill, go to hospital and say, “the government must do something”.

President Thabo Mbeki⁵³

We have had enough of the slipperiness and prevarication of all the politicians, elected by us, who declare us ‘irresponsible’ when we remind them of the promises they made us.

Pierre Bourdieu⁵⁴

The question of who is responsible for providing for the needs of people living with HIV and AIDS has been a critical one in South Africa’s emerging democracy. This question has revealed that the meanings of “democracy”, “citizenship” and “human rights” are not self-evident but highly contested. The flexible way in which these terms are defined results in a politics of inclusion and exclusion that all too often works against marginalised groups – the homeless, landless, economically impoverished, women, children, and people living with HIV and AIDS.

It is also this question of rights and responsibility regarding people living with HIV and AIDS that has most starkly foregrounded the power of the post-apartheid state over life and death. The South African Bill of Rights states unequivocally that “Everyone has the right to life.” The Bill of Rights also contains the following statement: “Everyone has the right to bodily and psychological integrity, which includes the right to make decisions concerning reproduction and to security in and control over their body”. Under the

⁵³ Mbeki (2002:1)

⁵⁴ Bourdieu (1998:78)

heading of “Health care, food and water and social security” the Constitution reads as follows:

Everyone has the right to have access to: health care services, including reproductive health care; sufficient food and water; and social security, including, if they are unable to support themselves and their dependants, appropriate social assistance. The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights. No one may be refused emergency medical treatment.

The duty of the state, as defined in The Bill of Rights, is to take measures, “to achieve the progressive realisation of each of these rights”. The “right to have rights” for all those living in South Africa distinguishes the post-apartheid dispensation from the apartheid state. The South African AIDS activist movement the Treatment Action Campaign have made powerful use of the judicial system to bring the state to account for their failure to fulfil their constitutional duties regarding the provision of treatment for people living with HIV and AIDS. In spite of the victories the activist movement has won, the epidemic has thrown into sharp focus the all too frequent disjuncture between the letter of the law and the way in which it is translated into practice.

In their landmark case against the National Department of Health in 2001, the Treatment Action Campaign claimed that the state had a constitutional duty to provide anti-retroviral therapy to prevent the transmission of HIV from mother to child. They took the government to court and won the case. The government appealed against the ruling and the case was sent to the Constitutional Court. The Constitutional Court ruled that the state had to provide treatment to all pregnant women in the public health care system as a matter of urgency. The government was compelled to comply with the court’s order, but they did so slowly, with great bureaucratic somnolence, an immense foot-dragging that has taken a vast toll in human lives.

How can we understand the failure of the South African state to adequately address the needs of people living with HIV and AIDS? Public debate around this issue has been intensely polarised. Commentators have accused the state of a new apartheid, culpable homicide, and even of genocide.⁵⁵ High-ranking government officials, including

⁵⁵ See Tutu (2004). As part of their 2003 civil disobedience campaign the Treatment Action Campaign accused the Minister of Health Manto Tshabalala Msimang of culpable homicide. Zackie

President Mbeki, have retorted that such critics are racist, afro-pessimists and hood-winked by the multi-national pharmaceutical industry.⁵⁶ Few thinkers have engaged with the question of why the state has held their widely unpopular position on the epidemic for so long in any depth, nor has there been an adequate analysis of how it has been possible for the lives of so many to have been made expendable. One notable exception in this regard is Ulrike Kistner's study *Commissioning and Contesting Post-Apartheid's Human Rights* (2003). Although she describes her project as "complicit with the belated arrival of a debate on human rights in South Africa, at a point where the political and social basis for such a debate is receding", her analysis offers a critical starting point for any attempt to address the nature of state power in post-apartheid South Africa (Kistner, 2003:1).

In charting how the universal extension of civil rights in South Africa has not been accompanied by the realisation of socio-economic rights, Kistner draws attention to a conflict she describes as "endemic to constitutional democracies" (2003:3). This conflict lies in how civil rights can only be substantive once socio-economic rights have been realised as it is the realisation of socio-economic rights that makes participation within the political possible. Kistner notes that activist groups in South Africa have drawn on the state's obligation to progressively realise socio-economic rights in their legal claims. However, she observes that "socio-economic rights do not amount to enforceable obligations" as unlike civil rights "they are not absolute, but programmatic, qualified rights" (5):

Their fulfilment, through placing a minimum core obligation on the state, is made dependant on available resources. Thus while the Constitution uniquely includes socio-economic rights in its Bill of Rights, the judicial enforcement of these rights has become the Achilles' heel of the South African government's social policy. (Kistner, 2003:5)

The divergence between civil and socio-economic rights marks what Kistner terms "the unexpected return of questions of the right to and power over life" (3). In her analysis of the post-apartheid state's response to the HIV and AIDS epidemic, Kistner draws on Foucault's articulation of bio-power and of bio-politics and on Agamben's conception of the persistence of sovereign power in the contemporary global order. She reads the South

Achmat has referred to the state's AIDS policies as a "holocaust against the poor". See Cameron (2005:222).

⁵⁶ See Mbeki's ZK Matthews Memorial Lecture (2001). See also Tshabalala Msimang (2004).

African government's position on HIV and AIDS "not simply as a matter of state oppression and presidential lunacy, but as definitive of a new way of exercising political power in matters of life and death – a type of power that we can ill afford to ignore in our contestations" (3). For her, attempts to explain the state's position on HIV and AIDS by accusing the government of "lunacy and irresponsibility", "constitute a lapse of historical-critical analysis" (1). Like Kistner I argue here that "pronouncing the South African government's stance on HIV and AIDS 'lunatic', 'eccentric', 'idiosyncratic', 'quixotic', 'bizarre', while not unmotivated, [...] obscures some of the fundamental shifts in bio-politics in relation to race, nation-state, public health and human rights" (1).

In a chapter focusing explicitly on sovereign power, bio-politics and HIV and AIDS in South Africa, Kistner shows how the transition from sovereign power to bio-power has not been as complete as Foucault claims. She points to how Foucault in fact had to recognise the persistence of sovereign power within the bio-political in order to account for fascism and Nazism. She also argues that Foucault's account of the emergence of bio-politics is complicated in colonial and post-colonial contexts by the fact that under colonialism the processes of individualisation and normalisation that mark the emergence of bio-power were not in place. She argues for a recognition of the ways in which sovereign power has returned (if, in fact, it ever receded) and perceives a continuum between forms of power in the colonial and post-colonial state. She argues that rather than the political becoming biologised in the post-apartheid state (bio-politics) the biological has become politicised (sovereign power) (152). However, Kistner does acknowledge that "the ancient right of sovereignty over bare life [...] returns under historically changed and changing circumstances" (154).

The extension through technology, of the sphere of culture into that of nature, the innovations of biotechnology, the changing role of the nation state, the disappearance of social security, the social degradation left by social inequalities and the social devastation caused by the prevalence of HIV/AIDS, have provided new contours for the relation between sovereign power and bare life. (154)

In her desire to show how Foucault too readily dismissed sovereign power in his analysis of the emergence of the new era of bio-politics, Kistner in turn too quickly dismisses those aspects of Foucault's argument that can be usefully applied in analysing precisely the "new contours for the relation between sovereign power and bare life" that are made

manifest in post-apartheid South Africa in the time of AIDS. The argument Kistner makes is compelling and intersects with my own understanding of the position of the state in relation to people living with HIV and AIDS. However, there are two areas of focus that I take up here that illuminate some differences in our ways of thinking about some of the problems that emerge through thinking about the epidemic in South Africa in relation to bio-politics and bare life. The first concerns how sovereign power comes to be reinstated within the political order of constitutional democracies, which, through Foucault, I argue below emerges through the bio-political division between those who must live and those who can be allowed to die.

The second difference between the argument Kistner makes and that which I am making here concerns the complex relation between people living with HIV and AIDS in South Africa and the state. Against Kistner I argue that this relation is not that which operates between the sovereign and subject, but instead is one marked by the contest and interaction between sovereign power and bio-politics. At the same time as people living with HIV and AIDS have been cast as the living dead, treatment activists have staked a claim to inclusion within the political on the same grounds that have served as the means for their exclusion – their sero-positive HIV status. This claim to biological citizenship refutes sovereign power over life and death and constitutes a challenge to the exclusivity of the bio-political state. However, as Kistner shows, what has been exposed in contemporary South Africa is the persistence of sovereign power in the form of the modern constitutional democracy. While the consequences of the persistence of sovereign power over life and death are everywhere in evidence, we have not yet properly understood how the production of expendable populations continues to be possible nor of the philosophical and political implications of the normalisation of ever-expanding “death-zones”.⁵⁷

Kistner’s analysis of the divide between civil rights and socio-economic rights leads her to conclude that while marginalised groups in South Africa may hold civil rights, they are directly exposed to the power of the state over life and death, to sovereign power. While I agree that the HIV and AIDS epidemic marks a particularly clear instance

⁵⁷ “The globalised world is tendentially divided into life-zones and death-zones – a division frequently reproduced within the boundaries of a single country or city, giving rise to the apparently paradoxical phenomenon of ‘citizens without rights’”(Kistner, 2003:154).

of the power of the state over the lives of its subjects, Kistner does not account for how the unequal distribution of rights has been and continues to be made possible nor does she explain how it has been possible for the state to assume the position of the sovereign in relation to people living with HIV and AIDS. Under true sovereign power all lives are equally exposed to the power of the state. This is clearly not the case in contemporary South Africa where those wealthy enough to afford private health care are protected from the public health system and the state's sovereign power over life and death. And as the TAC has shown, it is possible to move, although with great difficulty, from a position exposed to the sovereign power of the state to one in which one's rights to biological citizenship are recognised.

How then do we understand the co-existence and even the intersection between sovereign power and bio-power? In the section that follows I argue that the state has assumed sovereign power over life and death through bio-political means: through the production of an expendable population, the production of people living with HIV and AIDS as the living dead. In this way people living with HIV and AIDS are effectively biologised out of the political. In order to make this argument I return to Foucault and his account of the emergence of bio-politics in order to understand the persistence of sovereignty within a state whose ostensible objective is bio-political: to make live.

Marked for death

Foucault's articulation of the emergence of bio-power and of bio-politics provides a fruitful way to think through how and why rights come to be unevenly distributed within societies and across the global political order. In the final section of *The History of Sexuality Volume One* (1978), Foucault argues that the distinction between killing and letting die marks the distinction between two different kinds of state power, sovereign power and what he terms "bio-power": "One might say that the ancient right to *take* life or *let* live was replaced by the power to *foster* life or *disallow* it to the point of death" (138). Foucault writes that from the seventeenth century onwards the power of the state was no longer constituted through the ability to bring about death but rather through the

administration of life. This new concern with the life of populations led to the proliferation of discourses and institutions concerned with the regulation, administration and management of all aspects of life. The expansion of the power of the state into every aspect of life meant that the state became the determining force in the life of populations. In fact, it was precisely at this time and through the vast social machinery set up to monitor, measure and regulate human life that the very concept of “the population” emerged.

What we are dealing with in this new technology of power is not exactly society (or at least not the social body, as defined by the jurists), nor is it the individual-as-body. It is a new body, a multiple body, a body with so many heads that, while they might not be infinite in number, cannot necessarily be counted. Biopolitics deals with the population, with the population as political problem, as a problem that is at once scientific and political, as a biological problem and as power’s problem. (245)

In a time prior to the formation of the state apparatuses and institutions such as hospitals, schools and prisons, the state obviously had a limited ability to intervene in the lives of its subjects. Foucault’s work draws attention to how the absence of such institutions also points to the fact that the state had no *interest* in intervening in the lives of its subjects.

Foucault distinguishes what he terms “the anatomo-politics of the human body established in the course of the eighteenth century” from “a “bio-politics” of the human race (History of Sexuality, 139). While anatomo-politics took hold of individual bodies, subjecting them to multiple forms of disciplinary technologies, bio-power is directed towards “man as species” (2003: 242).

Unlike discipline, which is addressed to bodies, the new non-disciplinary power is applied not to man-as-body but to the living man, to man-as-living-being; ultimately, if you like, to man-as-species. To be more specific I would say that discipline tries to rule a multiplicity of men to the extent that their multiplicity can and must be dissolved into individual bodies that can be kept under surveillance, trained, used, and if need be, punished. And that the new technology that is being established is addressed to a multiplicity of men, not to the extent that they are nothing more than their individual bodies, but to the extent that they form, on the contrary, a global mass that is affected by overall processes characteristic of birth, death, production, illness, and so on. (Foucault, 2003: 243)

To occupy a place within the bio-political order is to be made subject to disciplinary forms of power that serve to regulate the practices of everyday life. It is also to be entered into the realm of the political not as an individual subject but as part of the larger social

whole. Under this form of power one becomes part of the social body by virtue of having life. While the thorough penetration of every aspect of life by power may not seem like a state of affairs we would rationally will, to be cast out of the social world regulated by power is to be unmade as a subject. In order to have rights a person must be recognised as a subject by those institutions that secure those rights. To be cast outside of the social does not mean that one is no longer subject to power. Rather it is no longer to be protected by those institutions of power that, paradoxically, serve to protect us *from* power. In this new formation of power in which the work of the state is to safeguard the right to life and not to kill, disallowing life is the way in which the state brings about death.

If it is true that the power of sovereignty is increasingly on the retreat and that disciplinary or regulatory disciplinary power is on the advance, how will the power to kill and the function of murder operate in this technology of power, which takes life as both its object and its objective? How can a power such as this kill, if it is true that its basic function is to improve life, to prolong its duration, to improve its chances, to avoid accidents, and to compensate for failings? How, under these conditions, is it possible for a political power to kill, to expose not only its enemies but its own citizens to the risk of death? Given that this power's objective is essentially to make live, how can it let die? How can the power of death, the function of death, be exercised in a political system centred upon bio-power? (2003:254)

The answer Foucault provides is racism, which he describes as “primarily a way of introducing a break into the domain of life that is under power's control: the break between what must live and what must die” (2003:254). In the last of his lectures delivered at the College de France in 1976, Foucault describes bio-power's relation to racism, and the ways in which racism manifested in Nazism and Socialism. Foucault identifies two ways in which racism is mobilised in the service of bio-power. The first consists in “fragmenting the field of the biological that power controls” and “of separating out the groups that exist within a population” (255). Secondly, racism operates to “make the relationship of war – “If you want to live, the other must die” – function in a way that is completely new and that is quite compatible with the exercise of biopower” (255)

On the one hand racism makes it possible to establish a relationship between my life and the death of the other that is not a military or war-like relationship of confrontation but a biological-type relationship: “The more inferior species die out,

the more abnormal individuals are eliminated, the fewer degenerates there will be in the species as a whole, and the more I – as species rather than individual – can live, the more vigorous I will be. I will be able to proliferate.” The fact that the other dies does not mean simply that I live in the sense that his death guarantees my safety; the death of the other, the death of the bad race, of the inferior race (or the degenerate, or the abnormal) is something that will make life in general healthier: healthier and purer. (2003:255)

Importantly for the connections I am trying to draw between bio-power and the position of the South African state in relation to people living with HIV and AIDS, Foucault defines “killing” in the following way: “When I say ‘killing,’ I obviously do not mean simply murder as such, but also every form of indirect murder: the fact of exposing someone to death, increasing the risk of death for some people, or quite simply, political death, expulsion, rejection and so on” (256). Foucault’s analysis of how bio-power’s ability to disallow life has brought about more deaths than the exercise of the sovereign right to take life is a chilling diagnosis of how modern forms of power over life work through disqualifying certain members of a population from being categorised as human.

The modern state can kill not only individuals but whole populations. If genocide is indeed the dream of modern powers, this is not because of a recent return of the ancient right to kill; it is because power is situated and exercised at the level of life, the species, the race, and the large-scale phenomena of population. (Foucault, 1978:137)

Where sovereign power seized hold of the body only in order to subdue it, to kill, modern state power “interferes” with life and takes hold of productive and reproductive bodies in order to control both individual bodies and the body politic. This argument provides a way to understand why the body has become a site of intense anxiety and concern for the modern nation state and to think about why the AIDS epidemic presents a crisis for the state in its management of the body politic. HIV and AIDS, as signifiers of the unmanageable and uncontrollable aspects of human life, pose a decided threat to contemporary manifestations of state power which seize hold of the body in order to administer life.

In her analysis of the operation of sovereign power in contemporary South Africa, Kistner claims that the state has asserted its sovereign right over life and death, not on biological grounds but in a way that is “directly political”:

The new regime of bio-politics that draws bare life directly into the political domain, does not rely on racial categorisation or on the notion of a biologically defined 'internal enemy' for its logical coherence or legitimacy (if, indeed, it is concerned about social legitimacy at all). It has become directly political. (Kistner, 2003:15).

While Kistner's analysis of the persistence of sovereign power in post-apartheid South Africa takes the HIV and AIDS epidemic as proving-ground, she does not attend to how the widespread stigma that is attached to the condition has been both fuelled and utilised by the state to diminish the need to justify and legitimise their position. Like racism and anti-semitism, discrimination against people living with HIV and AIDS is made possible through the stigmatisation of HIV-positive people as a group. Against Kistner's view I argue here that people living with HIV and AIDS have indeed been cast as the "internal enemy". This is evident even in the way that the state continues to focus on prevention campaigns to prevent the spread of HIV to the uninfected members of the population rather than addressing the needs of people living with HIV and AIDS. It has been all too easy for the state to disregard the rights of HIV-positive South Africans, the majority of whom are economically impoverished, socially marginalised, landless and homeless. Just as the early years of the epidemic were characterised by the disregard for the rights of gay men, Haitians, and injecting drug users, those Simon Watney has termed "expendable populations", in the contemporary global order the lives of impoverished black Africans living with HIV and AIDS are not considered worth saving.

Not surprisingly in a context where so few people have access to anti-retroviral therapy, many South Africans who are diagnosed HIV-positive feel as if they have been handed a death sentence. Before the state consented to provide anti-retroviral treatment, people who grew sick with AIDS were effectively given over to death, by their families, by the medical practitioners who were not permitted to treat them, and by the state. In the section that follows I consider how people living with HIV and AIDS in South Africa have been marked for death. I argue that the distinction between the living and the dead has been collapsed in the context of the epidemic in South Africa and that people living with HIV and AIDS have been identified by the state as "dying-subjects". In my analysis I show how bio-politics makes possible the re-emergence of the sovereign power of the state to determine who qualifies as living and who can be left for dead. I argue that the

categorisation of people living with HIV and AIDS as dying, or as the living dead, is a medicalisation of the racist classification of who qualifies as properly human and who may be cast out of the realm of the living.

“Dignity” without life

The right to life is, in one sense, antecedent to all the other rights in the Constitution. Without life in the sense of existence, it would not be possible to exercise rights or to be the bearer of them. But the right to life was included in the Constitution not simply to enshrine the right to existence. It is not life as mere organic matter that the Constitution cherishes, but the right to human life: the right to share in the experience of humanity. This concept of human life is at the centre of our constitutional values. The Constitution seeks to establish a society where the individual value of each member of the community is recognised and treasured. The right to life is central to such a society. The right to life, thus understood, incorporates the right to dignity: without dignity, human life is substantially diminished. Without life, there cannot be dignity.

Kate O'Regan⁵⁸

Death, Foucault tells us, is power's limit point, the body's escape from the hold of modern state power. Understanding how the dying and the dead are abandoned by power limit is a productive way to think through the relation between the state and people living with HIV and AIDS who, I argue here, have been marked for death. The living who are given over to death in life are positioned beyond the reach of the technologies of power, beyond the reach of rights. It follows that if power cannot reach the living dead, there is no need to regulate them. If power's mode is regulation and there is no way to regulate the living dead, then they are positioned outside of rights.

In order to take the life of another person, that person must be living. It is this capacity to be killed that defines the living being. The dead are those who cannot be killed because they are no longer alive. This vulnerability to death marks the human. It is also only possible to *allow* someone to die if they are already dying and there is nothing

⁵⁸ South African Constitutional Court Judge, Kate O'Regan, *The Bill of Rights Handbook* (1999:220)

that can be done to avert their death. In South Africa in the context of the HIV and AIDS epidemic, the distinction between those who are sick and those who are dying has been collapsed. People who are sick are people who are living; they can be treated and it is their living bodies that are made subject to medical care. The dying person occupies a place between the living and the dead. Those who are dying already belong to death in that the dying person cannot be saved. The spaces of the sick are the clinic and the hospital. The spaces of the dying are the hospice and the home. For the dying there is little that can be done other than the alleviation of suffering. Until November 2003 the state's HIV and AIDS programmes concerned themselves with the living (voluntary counselling and testing, education and awareness, the promotion of abstinence, the distribution of condoms) and with the dying (the provision of "end of life care"). Those who were living with HIV and AIDS and who became ill were effectively administered out of existence.

At the beginning of 2003 an examination of the website of the South African Department of Health was a sobering experience. At the time approximately 1000 South Africans died of AIDS each day and there were approximately the equivalent number of new infections. The Treatment Action Campaign were calling for the state to implement a comprehensive national treatment plan to address the needs of people living with HIV and AIDS in the public health sector, but no mention of the treatment plan appeared on the site. In a section concerning the treatment and care of people living with HIV and AIDS was a sentence that included the bracketed clause "(no ARV's)". The Department of Health seemed implacable in the face of local and international criticism and the growing mortality figures.

The newsletter of the National HIV/AIDS and TB Programme, regularly published on the Department of Health website, can be read as representative of the official rhetoric of the time. The 15 January 2003 edition contains an article entitled "Mobilizing Communities in the Fight Against AIDS" that describes a project set up by the Department of Health in association with non-governmental organisations to provide "end of life care" for people living with HIV and AIDS:

The need to develop community support systems to assist AIDS patients in South Africa has never been stronger. Since 1999, the innovative Bambisanani Project has worked to address the urgent need for home-based AIDS care in some of the most

devastated areas of South Africa. The Project is serving as a community mobilization model nationwide and proves that community support is crucial to successful health programmes. ... Despite what seems to be a depressing situation, one need only remember that before home care, families had no one to turn to as loved ones died in more pain – and with less dignity. (Urdaneta, 2003)

While any form of support for people living with HIV and AIDS might be thought better than none at all, the Bambisanani project can hardly be termed a “successful health programme”. Far from being concerned with restoring those who are ill to a state of health, the aim of the programme is to assist people to die. The section of the article that describes how the project works in practice begins with a quote from a tribal chief in the Kwampisi area: “We cannot be given things, we must build them ourselves.” This statement de-legitimises the claims made by people living with HIV and AIDS on the state and places the burden of responsibility for the provision of treatment and care on those who are sick and on their families. It is clear that in a context in which people do not have the means to provide for themselves, and are so sick that they can barely lift themselves from the floor of their mud huts, they must be given things. What they need most of all is medical treatment. The newsletter continues in the following way:

One of Kwampisi’s AIDS sufferers is 30-year old Ziketile. He was a sugar cane worker and the only employed member of his family until one year ago, when he became ill. With active tuberculosis, and exhibiting all the symptoms of full-blown AIDS, tears roll down his cheeks as he sits up: “I don’t want to die.” He feels guilt coupled with physical pain. A woman named Busi is the local home-based care supporter who identified Ziketile’s need for additional home care. Busi visits Ziketile almost every day. She gives his mother relief from the 24-hour job of caring for her son. Though watching her son die is a tragedy, Ziketile’s mother appreciates the help she has been given: “*It is so helpful to have Busi’s support.*” Today, Busi offers advice about massaging Ziketile to alleviate some of his pain. She uses items in the home care kits daily. The aspirin provides pain relief, and the disinfectant helps keep her son’s bed – on the floor of a mud hut – as clean as possible. In addition to helping AIDS and other terminally ill patients spend their days with family, each case is helping to overcome the stigma of AIDS in communities. Neighbours and friends enlist to help. Most importantly, AIDS victims feel support. In Ziketile’s own words: “*It is so good to have warmth in the house.*” (Urdaneta, 2003)

Ziketile, described here as a person with “active tuberculosis” and as, “exhibiting all the symptoms of full-blown AIDS” is by now certainly dead. In spite of the fact that medication exists that would alleviate his pain and prolong his life, Ziketile is given only

aspirin and “support”. It is interesting to note that statements made by Ziketile and by his mother are italicised in this piece; all except for five words that I wish to draw attention to here:

“I don’t want to die.”

These words are spoken by Ziketile, who is extremely ill and who cries as he confesses that in spite of the “death-with-dispirin-dignity” the Department of Health intends for him, he does not want to die. The next sentence informs the reader that besides physical pain, Ziketile feels guilty, as if, in place of stating “I don’t want to die”, he had said, “I don’t want to die, but I know that I deserve to die.”

Against Tragedy

Tragedy – drama of elevated theme and diction and with unhappy ending; sad event, serious accident. Oxford English Dictionary

Why should Ziketile want not to die? Caught up as he is in the machinations of the public health system within which his dying is tragic, his death inevitable and in any event, his own fault, there is no place for his desire to live. Ziketile is suffering from several major opportunistic infections all of which, coupled with the guilt the author infers he feels (presumably because of his HIV-positive status), are reduced to a form of punishment here. Quite why Ziketile should be consumed by guilt is not made clear. That he is described as a “victim” only confuses matters further. Who exactly is Ziketile a victim of if it is Ziketile himself who is guilty? Within this tragic narrative, Ziketile is a victim of his own desire, a discursive move that allows the state to neatly evade responsibility for providing for his well-being.

In her essay entitled “AIDS: Keywords”, Jan Zita Grover analyses the rhetorical force in naming people living with HIV and AIDS, “victims”. She writes that “Victims always end up revealing some tragic character flaw that has invited their tragedy” (29). The fact that Ziketile is judged to be guilty makes his death inevitable. For after all he has

done something (that remains unnamed), for which he has been punished and for which there can be no other end than death. She argues that the use of the term “victim” is bound to a fatalism that “implies that nothing, or next to nothing, can be done about the cultural, social and medical crises presented by AIDS. It denies the very possibility of all that is *in fact* being done by people living with AIDS and those working with them” (29).

The fatalism of the article that appeared on the Department of Health website is all the more alarming given the existence of anti-retroviral therapy. If Ziketile had access to anti-retrovirals he could live an additional twenty years or more and die with dignity when nothing further could be done to prolong his life. There can be no death with dignity if the dignity of the person is not respected in life. If we follow the logic of the article describing Ziketile’s plight to its conclusion it becomes clear that he, as a poor person with AIDS, cannot be given anti-retroviral therapy since it is his responsibility to provide for himself and in the end there is nothing that can be done for him since he has victimised himself to death. Grover concludes,

A patronage that simultaneously grants “victims” powerlessness and then assigns them blame for their condition is nothing new. It is therefore important to make connections between the construction of AIDS victimhood and the similar constructions of the poor, who also suffer the triple curse of objectification, institutionalised powerlessness, and blame for their condition. (30)

Ziketile is condemned to death because he is understood to have brought about his own death. Because he is guilty he cannot be saved. In this way Ziketile’s claim on his right to life is wrested from him. His five small words, “I don’t want to die” grow smaller and smaller as he is unmade as a subject with rights, a subject who can refuse the inexorable logic of the state’s administration of his death.

In its invocation of tragedy this article intersects with representations of Africans living with HIV and AIDS that dominate in the mainstream media in the west⁵⁹. Such representations turn the HIV and AIDS epidemic into little more than an accident of nature or a sad twist of fate. Once it is understood as part of the workings of the bio-political state, however, the inevitability of Ziketile’s death can not be considered a tragic accident.

⁵⁹ See my critique of the discourse of “African AIDS” in the following chapter.

Prior to November 2003 when the state announced that they would begin to provide treatment for people living with HIV and AIDS in the public health sector in South Africa, HIV-positive South Africans were subject to both civil and social death. As noted above, AIDS activists in South Africa have successfully contested the bio-political expulsion of people living with HIV and AIDS and laid claim to civil rights. At the same time AIDS activists in South Africa, in particular the TAC, have powerfully refuted the categorisation of people living with HIV and AIDS as socially dead. In spite of this, many HIV-positive South Africans continue to live in silence and fear and are subject to discrimination which presents a serious obstacle in gaining access to treatment and care. While treatment is (theoretically) universally available to all who need it, and the rights of people living with HIV and AIDS have been recognised by the state, those who endure a social death, while technically not civilly dead, are in a state of suspension between death and the law.

In the following section I trace the history of the concept of “social death” which has been used to describe the situation of those who are living and yet not accorded the rights of the living. In this way these individuals endure what can be termed a social death – they remain physically alive but occupy a subject position that is neither alive nor dead. The concept of social death and in particular, the way in which it has been developed by Giorgio Agamben, provides a way to understand how such spaces of suspension between life and death have become an accepted part of life in contemporary society.

I draw on the work of Orlando Patterson on the position of the slave, Frantz Fanon on the “non-being” of the colonised subject, and Jean Amery’s articulation of the figure of the living dead, the Muselmann, in the Nazi death camps. In my reading of Amery’s testimonial account I draw on Giorgio Agamben’s analysis of the impossible possibility of bearing witness to the living dead. These conceptualisations of social death provide a way to articulate conditions of life in contemporary South Africa for people living with HIV and AIDS.

Social death

The tradition of the oppressed teaches us that the “state of exception” in which we live is the rule. We must arrive at a concept of history that corresponds to this fact. Then we will have the production of the real state of exception before us as a task.

Walter Benjamin⁶⁰

If one establishes a limit beyond which one ceases to be human, and all or most of humankind passes beyond it, this proves not the inhumanity of human beings but, instead, the insufficiency and abstraction of the limit.

Giorgio Agamben⁶¹

Bio-power helps us to think through how power comes to be concerned with seizing hold of life, of controlling and administering it, and consequently, why modern states are singularly disinterested in the lives of the dying. But in some ways it sets up too distinct a binary between those who may be considered living and those who are dying, those who are socially dead. How do we account for those large sections of every population of the marginalised, the abject, all those who live in conditions of life that cannot properly be understood as “life”?

In his essay entitled “Necropolitics”, Achille Mbembe argues that “the notion of biopower is insufficient to account for contemporary forms of subjugation of life to the power of death” (Mbembe, 2003:39). Mbembe writes that “In Foucault’s formulation of it, biopower appears to function through dividing people into those who must live and those who must die” (2003:16-17). If bio-power works through the division of those who may live and those who must die, how do we account for those who are living in the mode of dying? Mbembe articulates “necropolitics” as the way in which power works in the service of death. He argues that necropolitics results in “the creation of *death-worlds*, new and unique forms of social existence in which vast populations are subjected to conditions of life conferring on them the status of *living dead*” (2003: 40).

The production of the living dead, those who fall outside of the category of the human and who are denied the rights ordinarily accorded to the living, is not a

⁶⁰ Benjamin cited in Agamben (1999:55)

⁶¹ Agamben, (2002:63)

phenomenon particular to the present. In *Slavery and Social Death*, Orlando Patterson's brilliant analysis of the ontology of slavery, he argues that "in almost all slaveholding societies" the slave was defined "as a socially dead person" (Patterson, 1982:39). "The slave was natally alienated and condemned as a socially dead person, his existence having no legitimacy whatever" (1982:337). The slave lives only in relation to the master and is denied all connection to his or her own family or community. In this way the slave is made to occupy a place outside of the social, a place on the margin between life and death, and is made an object in what Patterson terms "a relation of domination" (334). The paradox of slavery is that in order to be a slave the slave had to be a non-being. "Enslavement was separation (or symbolic execution), slavery was a liminal state of social death, and manumission was symbolic rebirth" (293). Slaves were deprived of civil rights but this did not imply that they were not subject to the law. Patterson observes that slaves were held to be "legally and morally responsible" (22) for their actions and thus were recognised by the law. At the same time the life of the slave was not the property of the slave but of the master. The social death of the slave was underpinned by the threat of physical death: "The slave was the ultimate human tool, as imprintable and as disposable as the master wished" (7). The body of the slave could be replaced and thus was dispensable. The life of the slave was preserved only as long as it was of use to the master and the value of the slave's life was determined by, and in relation to, the master. The life of the slave had no value in and of itself and it is in this sense that the life of the slave was not recognised as life.

Slavery is one instance of the way in which life itself can be taken from the living while they are biologically alive to produce what Frantz Fanon, in *Black Skin, White Masks*, terms "a zone of non-being" (Fanon, 1967:10). Fanon does not use the term "social death" but his analysis of colonial relations of power vividly articulates the "unbecoming" of the colonised subject under colonial domination. For Fanon "every ontology is made unattainable in a colonized and civilised society" (1967:109). He identifies what he terms an "inner kinship" (113) with his ancestors who had been enslaved and lynched and writes:

Ontology – once it is finally admitted as leaving existence by the wayside – does not permit us to understand the being of the black man. For not only must the black man be black; he must be black in relation to the white man. Some critics will take

it on themselves to remind us that this proposition has a converse. I say that this is false. The black man has no ontological resistance in the eyes of the white man. (1967:110)

For Fanon, colonisation is the negation of the black person's very being. As in Patterson's analysis of the relations of domination between the master and the slave, the being of the coloniser is affirmed through the negation of the being of the colonised. The colonised person, like the slave, is subject to the law and yet not recognised as a subject by the law. Cast out of the spheres within which their lives would be recognised as having value in and of themselves, the colonised person and the slave occupy the position of the living dead.

During the Second World War the extermination of whole peoples was accorded a precise and terrible logic. The right to life belonged only to those who were considered human. Those who were not considered human were condemned to death. The spaces of the Nazi death camps were spaces of social death *in extremis*, spaces in which life ceased to be recognisable as life and in which death could not be recognised as death. It is only the living being who can die. In the camps death replaced life as the mode of being. It is not possible to die if you are already dead. In *At the Mind's Limits: Contemplations by a Survivor on Auschwitz and its Realities*, Jean Amery refers to those who were incarcerated in the Nazi death camps and known as "Muslims" or "*Muselmänner*" and who can be understood as archetypal figures of the living dead:

In any event, it is clear that the entire question of the effectiveness of the intellect can no longer be raised where the subject, faced directly with death through hunger or exhaustion, is not only de-intellectualized, but in the actual sense of the word dehumanised. The so-called Mussulman, as the camp language termed the prisoner who was giving up and was given up by his comrades, no longer had room in his consciousness for the contrasts good or bad, noble or base, intellectual or unintellectual. He was a staggering corpse, a bundle of physical functions in its last convulsions. As hard as it may be for us to do so, we must exclude him from our considerations. (1966, 1999:9)

For Amery, the figure of the *Muselmänn* is that which cannot be approached. Although the *Muselmänn* remained alive the life of the *Muselmänn* could not properly said to be life, "he was a staggering corpse". The *Muselmänn* crosses the border between life and death to occupy an impossible place, Fanon's "zone of non-being". It is this problematic

of the figure of the living dead that Italian philosopher Giorgio Agamben takes up in *Remnants of Auschwitz* (Agamben, 1999).

Agamben identifies the figure of the *Muselmann* as that which is described as a state of being beyond the bounds of the human in accounts of those who survived the death camps. Agamben reads Amery's verdict that the figure of the *Muselmann* should be excluded from consideration in a strangely productive way. The entire second chapter of *Remnants of Auschwitz* is devoted to this figure of the *Muselmann* and is a refusal of the production of subjects that cannot be thought as subjects. Agamben's project in that work is to "listen to what is unsaid", for, he claims, those who survived the death camps bear witness to that which they claim to be unable to witness. Agamben writes that, "The paradoxical ethical situation of the *Muselmann* must be considered" (1999:63). He argues:

Simply to deny the *Muselmann*'s humanity would be to accept the verdict of the SS and to repeat their gesture. The *Muselmann* has, instead, moved into a zone of the human where not only help but also dignity and self-respect have become useless. But if there is a zone of the human in which these concepts make no sense, then they are not genuine ethical concepts, for no ethics can claim to exclude a part of humanity, no matter how unpleasant or difficult that humanity is to see. (Agamben, 1999: 63-64)

Through his readings of the testimony of survivors, Agamben undertakes to show how the unliveable condition of the *Muselmann* could not be thought and yet was lived. Agamben argues that the figure of the *Muselmann* does not represent the ends of the human but instead issues a demand for the formulation of an ethics of recognition. In *Remnants of Auschwitz* Agamben undertakes what can be understood as a redemptive project, to recognise the lives of those who were living but were considered dead and to resist the inhuman practices that prohibit the recognition of the human. And in this way, and through the testimony of those who bore witness to what could not be witnessed, to move towards an ethics without limits.

Towards an ethics of recognition

I wish to return again to Jean Amery's description of the *Muselmann*, the paradigmatic figure of the living dead, to argue that what constitutes life is not a condition of being objectively determined but a state of being conferred by and through others. In particular I wish to return to the moment in which Amery would give up the *Muselmann* yet encounters resistance both in himself and, I suggest here, from the *Muselmann* who persists in being human until the moment he is no longer recognised as such.

The so-called Mussulman, as the camp language termed the prisoner who was giving up and was given up by his comrades... (Amery, 1966,1999:9)

Here the *Muselmann* is one "who was giving up and was given up by his comrades". The *Muselmann* is one who had not yet "given up" but one who is "giving up". And yet the *Muselmann* has already been "given up" to death/for dead by his comrades. The *Muselmann* is giving up on living but the "giving up" cannot be separated from being "given up" by others. What is this hold on life that even the dying exert? And is this hold on life at the same time a hold on the living?

...as hard as it may be to do so, we must exclude him from our considerations.

(Amery, 1999:9)

What is this difficulty Amery identifies in turning away from the dying? What is it that the dying demand of the living? Why is it difficult to exclude the *Muselmann* from our considerations? To exclude the *Muselmann*, as Agamben suggests, is to be complicit with the Nazis and the processes of dehumanisation they intended. Yet this only partially explains why it is so difficult for Amery to turn away.

For philosopher Emmanuel Levinas, turning away from the other is turning away from ourselves. The figure of the person in close proximity to death is the human at its most vulnerable. For Levinas it is this vulnerability that marks the human. If we cannot face the vulnerability of the human and recognise humanness in vulnerability, we cannot be human ourselves. In "Peace and Proximity", Levinas describes "The face as the extreme precariousness of the other" (1996:167).

By starting with this extreme straightforwardness of the face of the other (*autrui*), we have previously been able to write that the face of the other in its precariousness and defencelessness, is for me at once the temptation to kill and the call to peace, the “You shall not kill.” The face which already accuses me makes me suspicious but already claims me and demands me. The right of the human is here, in this straightforwardness of exposition, of commandment and of assignation, a right more ancient than all conferment of dignity and every merit. The proximity of the neighbor – the peace of proximity – is the responsibility of the ego for an other, the impossibility of letting the other alone faced with the mystery of death. Concretely, this is the susception of dying for the other. Peace with the other (*autrui*) goes that far. It is the whole gravity of love of the neighbor, of love without concupiscence (Levinas, 1996:167).

The “face of the other in its precariousness and defencelessness” is acutely realised in the figure of the *Muselmann* who appears before Amery in the space of the death camp where the ethical recognition of the human was intended to meet its end. The appearance of the *Muselmann* is at once for Amery “the temptation to kill and the call to peace, the “You shall not kill.” To turn away from the other is to bring about their death. It is this bringing about of the death of the other to which Amery cannot reconcile himself. Amery’s difficulty lies in having already recognised the *Muselmann* while at the same time facing the burden, perhaps even the impossibility, of bearing witness to the *Muselmann*, “as hard as it may be to do so, we must exclude him from our considerations.” To re-cognise implies acknowledging what it is you have already seen. This means that to not recognise someone as human is to disavow your knowledge of their vulnerability, to refuse your own witnessing, your own humanness. In this sense Amery’s turning away from the *Muselmann* is at the same time a turning towards his own death. The relation between the witness and the figure of the *Muselmann* indicates that what is at stake in recognition is being itself.

It is the politics of recognition that defines the limits of the human and the ethics of recognition that negates that limit. The question that remains is that of how to bring about an ethical politics of recognition. Amery’s struggle to recognise the living in the dying, to confer recognition upon those who occupy the space between life and death, founders against a politics that would give those lives up for dead.

Dying and social death

What is the relation between the slave, the colonised person, and those who were incarcerated in the Nazi death camps, to the present and more precisely to people living with HIV and dying of AIDS in post-apartheid South Africa?⁶²

In an article in the 11 January 2004 edition of the South African newspaper *The Sunday Independent* “ARV rollout too late for majority of infected” Noelene Barbeau writes that Manto Tshabalala-Msimang, the national health minister “criticised people who blamed the government for not handing out ARVs to people infected with HIV and AIDS”. Tshabalala-Msimang is cited as saying:

What people fail to realise is that not all of the people infected will receive ARVs, because some of them are too far gone. This is a major problem we are experiencing. People leave HIV testing for far too late. There are 5 million people infected in this country, but we are going to look at the 500 000 who are in need, if and when, we introduce the ARVs. (Barbeau, 2004:3)

The Minister of Health’s small phrase, “too far gone”, raises a series of large questions about what it means to set a limit to what constitutes the human. What does it mean to be classified as “too far gone”? And what is the definition of this category of being, if it is a category of being at all? In spite of the shift in state policy on HIV and AIDS, the state remains engaged in the production of a category of being that is simultaneously non-being, of those who cannot be considered subjects because they are ‘too far gone’.

In *Excitable Speech: A Politics of the Performative*, Judith Butler writes of how subjects come into being through the recognition conferred on them by others:

One “exists” not only by virtue of being recognized, but, in a prior sense, by being *recognizable*. The terms that facilitate recognition are themselves conventional, the effects and instruments of a social ritual that decide, often through exclusion and violence, the linguistic conditions of survivable subjects. (Butler, 1997:5)

In order to survive we must be recognised but in order to be recognised we must be recognisable. The state of being of those classified as “too far gone” falls outside of being which can be recognised as being. The unrecognisability of people living with HIV and AIDS within discourse takes material form in and through their bodies that quite literally

⁶² For an interesting consideration of the relations between social death, slavery and Genocide see Card (2003).

become unrecognisable both to themselves and to others. It is this dual process of desubjectivisation in discourse and debilitation through the symptoms of AIDS-related diseases that Eric Michaels has named “unbecoming”. In his book documenting his own unbecoming from AIDS Michaels plays on this term, one of the meanings of which refers to improper behaviour, the behaviour of someone you would not wish to approach. Unbecoming signifies the process of becoming ill and of dying. It also captures Michaels’ sense of living in a state of being that is not being, a state beyond the limit of what is thought to constitute the human. That which is difficult to look upon or approach is not that which cannot be approached. Rather it is that which people turn away from, that which they do not wish to recognise.

Agamben’s analysis of the figure of the *Muselmann* is an indictment of those who argue that people who are sick with AIDS-related diseases are “too far gone”. As I have sought to show here, while there may be a category of being within medical science of those who are beyond medical help, there should be no such category in the political realm. In the chapters that follow I seek to read some of the ways in which state policy is made manifest in and through the bodies of people living with HIV and AIDS in South Africa to interrogate what Paul Farmer has termed, “biological expressions of social inequality” (Farmer, 1999:262). The struggle for access to treatment for people living with HIV and AIDS has made the power of the state to determine life and death all too clear. But it also indicates how the state holds the power to confer life through recognition. The power of the modern state lies not in killing but in deciding upon whose life is considered to be of value, in deciding whose life is considered life. As I have sought to show here, it is crucial to resist the production of dying-subjects as it is only those considered to be living that can be saved. In contemporary South Africa there are approximately five million people who have been positioned beyond the limit of the human. As Agamben argues, “this proves not the inhumanity of human beings but, instead, the insufficiency and abstraction of the limit” (Agamben, 2002:63).

Chapter Three

Violent Imaginings: Representing Africa and AIDS

In the previous chapter I discussed how the extension of a particular kind of power, described by Foucault as “bio-power”, results in zones of exclusion. These are both literal, the abandonment to death of those who could be helped by anti-retroviral treatment, and figurative, the social death which results from the stigmatisation of those living with HIV and AIDS. In this chapter I show how representation is implicated in the production of people living with HIV and AIDS in Africa as the “living dead”. I argue that the HIV-positive bodies of African subjects appear in the media in such a way as to place them under a form of discursive erasure. Through an analysis of photographic images that exemplify this genre, the chapter shows how the discourse of “African AIDS” limits the ways in which HIV and AIDS in Africa can be thought and represented.

I begin by considering how “African AIDS” performs a powerful ideological function. It persistently operates to obfuscate the complex relations between the west and what is perceived as its outside and constitutes Africa as an absolute zone of death. Drawing on Roland Barthes writings on photography, I analyse a six page photo-essay depicting AIDS in sub-Saharan Africa, “Crimes Against Humanity”, by photojournalist James Nachtwey, that appeared in *Time* magazine in 2001. I also consider a series of images drawn from Arthur van Amerongen and Geert van Kesteren’s book, *Mwendanjangula! AIDS in Zambia* (2001). I read these images not only as signs of how Africa enters the cultural imaginary of the west as a space of death, but as performative works that affect how people live and die.

In the early years of the epidemic gay and lesbian activists, artists and writers in Europe and North America were highly articulate about how the failure of their governments to adequately address the HIV and AIDS epidemic was devastating their communities. Right from the beginning the ways in which people living with HIV were

represented was identified as a crucial aspect in how the epidemic progressed. The crisis of AIDS and the emergence of an “AIDS literature” in the late 1980s and 1990s intersected with the increasing visibility of gays and lesbians as a political constituency. The early writings about HIV and AIDS were almost without exception written by gay men who chronicled the progression of their own illness or bore witness to the lives and deaths of their lovers and friends.⁶³ Their work played a critical part in resisting the discursive erasure of the experiences of people living with HIV and AIDS in the west and, as a result in attaining treatment and care.

In her book entitled *Representations of HIV/AIDS*, Gabriele Griffin maps out the profusion of cultural responses to the epidemic in Europe and North America in the late 1980s and 1990s when HIV and AIDS was most publicly visible in the west (Griffin, 2000:1). Her work, like that of Simon Watney, Douglas Crimp and others, reveals that the activism of gay communities in North America and the UK kept HIV and AIDS on the cultural and political agenda.⁶⁴ The HIV and AIDS activist group, the AIDS Coalition To Unleash Power (ACT UP), was formed in New York in 1987 and became increasingly militant in their protests against the inaction of the state.

By the end of the 1990s, as access to anti-retroviral treatment became widely available in the west, AIDS activism outside of the developing world effectively died. Griffin notes that while HIV and AIDS once occupied a relatively central place in the public consciousness of the west, and particularly in North America because of the existence of ACT UP, this is no longer the case. Her work traces “the rise of HIV/AIDS as a disease pattern and its fall in visibility in the social imaginary of contemporary western culture” (10):

Always already associated with the other, HIV/AIDS managed only briefly to transcend the boundaries of the visible world to enter the visual, cultural imagination as a signifier of catastrophe, and then under very specific conditions in which a sense of HIV/AIDS being about unprecedented numbers of deaths among gay men was dominant, and the threat of an over spill into the community at large

⁶³ The work of writers such as Edmund White, Paul Monette, David Wojnarowicz, Derek Jarman, and Mark Doty in the United States, Eric Michaels, an American anthropologist who lived in Australia, and Michel Simonin, Jean Paul Aron and Alain Emmanuel Dreuilhe in France, formed a new literary genre, that of AIDS witnessing and testimony. See also the work of visual artists Keith Haring and Felix Gonzales-Torres, both of whom produced public artworks about HIV and AIDS. Notable AIDS witnessing texts by woman writers include Amy Hoffman’s *Hospital Time* and Jamaica Kincaid’s *My Brother*.

⁶⁴ See Watney (1987) and Crimp (1988).

seemed imminent. The seeming containment of both, the one through education and prevention work, mainly done from within the gay community, the other achieved only partially in northern and western communities where the rise of infection and disease among women, poor people and drug users continues to be ignored, has displaced the anxieties which guaranteed the scripto-visual space for HIV/AIDS intervention work. For many living in the UK and the USA, and other western countries, HIV/AIDS has clearly withdrawn behind an invisible boundary beyond which only the other resides. (2000: 10-11)

On the other side of the “invisible boundary” are an estimated 50 million people living with HIV and AIDS, 40 million of whom live in sub-Saharan Africa. While access to anti-retroviral therapy has meant that AIDS has become a chronic manageable syndrome for the majority of people living with HIV and AIDS in the west, for many in the third world, AIDS remains just as deadly as it did before the advent of treatment. HIV and AIDS now primarily affects those who already occupy the social and economic margins and whose infection with HIV only serves to render their struggles less visible.

In the early years of the epidemic cultural theorist Douglas Crimp noted the absence of representations of HIV and AIDS in places outside of Europe and North America. In the collection of essays he edited, *AIDS: Cultural Analysis/ Cultural Activism*, Crimp points to what he terms the “unevenness” of the volume: “there are lacunae I regret, the most important of which is attention to the cataclysmic problem of AIDS in the Third World, a problem about which one hears only a deafening silence in the dominant media in the U.S” (Crimp, 1988:15). Today the primary mode of representing HIV and AIDS in Africa in the mainstream media in the west is through the discourse of “African AIDS” which draws on a long history of racist stereotyping and depicts Africa as a space of dying and death. As a result, the growing crisis of HIV and AIDS in Africa remains largely invisible, for, as I argue in this chapter, the representation of people living with HIV and AIDS through the discursive frame of “African AIDS” is itself a form of negation.

Visual representation, and in particular, photographic representation, provides a rich source of material through which to analyse how the epidemic in Africa has been produced as an object of knowledge. Analysing photographs of people living with HIV and AIDS in Africa can also bring unequal relations of power into sharp focus. In the following section I consider the question of how photographic images can be read.

Related to this is the question of the performative force of representation and what it is that photographs *do*. I approach these questions through the writings of Susan Sontag and Roland Barthes, two compelling theorists of what might be termed the philosophy of photography.⁶⁵

After Life: Reading Photographic Images

[P]hotographic connotation, like every well structured signification, is an institutional activity; in relation to society overall, its function is to integrate man, to reassure him.

Roland Barthes⁶⁶

In her now classic work, *On Photography*, Susan Sontag explores the ubiquity and importance of photographic images in the industrialized countries of the west where, she argues, life can no longer be imagined without cameras to provide evidence of life itself and people “feel that they are images, and are made real by photographs” (1973:161). Sontag’s reflections on the symbolic power photographic images have come to hold in contemporary society can also be read as an attempt to make sense of photography, to provide an answer to the question: “What is a photograph?” “The photographer both loots and preserves, denounces and consecrates” (64-65), she writes, and though “there is a sense in which the camera does indeed capture reality, not just interpret it, photographs are as much an interpretation of the world as paintings and drawings are” (6-7). Sontag’s description of photography challenges the idea that photographic images merely capture the event or person portrayed, replicating and mirroring the real. For her, the photograph can be understood as an interpretation of the real and is, therefore, also interpretable.

The question “what is a photograph?” provides the central focus of philosopher Roland Barthes’s essay “The Photographic Message”. The answer he provides extends and complicates Sontag’s definition of photographs and her analysis of how they can be

⁶⁵ There are many other theorists of photography and of visual culture. Graham Clarke’s *The Photograph* contains a useful bibliographic essay on foundational works in the field (Clarke, 1997).

⁶⁶ Barthes (1977:31).

read. For Barthes, what one reads is not the image in itself but the ways in which the image has been constructed, transmitted and received. “What is the content of the photographic message? What does the photograph transmit?” (Barthes, 1977:16-17), he asks. How is an image constructed, what are its constituent parts? And crucially, what are the other images, visible or remembered, that are read alongside and in conjunction with the image, informing its meaning?

Barthes begins his essay with what he terms “the photographic paradox” (1977:16): “analogical perfection”, the absence of a code that translates the object into its image, defines the photograph which, at the same time, is a sign of something other than itself. The photograph appears to be “a mechanical analogue of reality”, a “*denoted message*” (18), and to describe it is to attach to the image a “*connoted message*, which is the manner in which the society to a certain extent communicates what it thinks of it” (17).

In front of a photograph, the feeling of ‘denotation’, or, if one prefers, of analogical plenitude, is so great that the description of a photograph is literally impossible; to describe consists precisely in joining to the denoted message a relay or second-order message derived from a code which is that of language and constituting in relation to the photographic analogue, however much care one takes to be exact, a connotation: to describe is thus not simply to be imprecise or incomplete, it is to change structures, to signify something different to what is shown. (Barthes, 1977: 18-19)

The rhetorical power of photographic images can be attributed in large part to this “mythical” (19) quality imparted by the photograph’s assertion of objectivity, or what Barthes terms the “purely ‘denotative’ status of the photograph, the perfection and plenitude of its analogy” (19). While in the first section of his essay Barthes acknowledges the special status of the photographic image as a continuous message without a code (17), he goes on to hypothesize “that the photographic message too – at least in the press – is connoted.”

Connotation is not necessarily immediately graspable at the level of the message itself (it is one could say, at once invisible and active, clear and implicit) but it can already be inferred from certain phenomena which occur at the levels of the production and reception of the message: on the one hand the press photograph is an object that has been worked on, chosen, composed, constructed, treated according to professional, aesthetic or ideological norms which are so many factors of connotation; while on the other, this same photograph is not only perceived, received, it is *read*, connected more or less consciously by the public that consumes

it to a traditional stock of signs. Since every sign supposes a code, it is this code (of connotation) that one should try to establish. (1977:19)

The photographic image is at one and the same time analogical and always already connoted. To look at an image is to interpret it and therefore to translate it into language. This secondary connotation, the meaning ascribed to the image, is both attached to the image and constitutes the image. "From this point of view," Barthes writes, "the image – grasped immediately by an inner metalanguage, language itself – in actual fact has no denoted state, is immersed for its very social existence in at least an initial layer of connotation, that of the categories of language" (29). Imagine a photograph that appears without any sign of when or where it was taken. Even such an image can be read: in being perceived the image is instantly embedded in an unending network of signs. The code of connotation is what makes the photographic image recognisable as an interpretable object and is the means by which the image is read. While for Sontag, the "force of a photograph is that it keeps open to scrutiny instants which the normal flow of time immediately replaces", for Barthes the photographic image is no more outside of time than those who view it (Sontag, 1973:112). For Barthes photographs do not "capture" a moment of the real to be seen again and again, but in responding to the image, it is the viewer, and the society of which they are part, that is laid open to scrutiny. The instant in time the photograph is intended to capture is perceived afterwards and it is in this after-time that the significance of the image comes to be constituted. In this sense photographs do not preserve life but instead create it, a perpetual after-life.

In the sections that follow I look at how photographs, particularly those that are structured in ways that make a claim to representing the "true" story of AIDS in Africa, affirm particular ways of seeing and knowing. I am interested in Barthes' contention that photographic images work to reassure those who view them, particularly in relation to images of bodies, and more specifically, the bodies of Africans, dying or dead. I return to this at the end of this chapter when I attempt to think through how it might be possible for photographic images to disrupt rather than affirm ways of seeing.

Representation and dehumanisation: the construction of “African AIDS”

The construction of ‘African AIDS’ tells us much about the west, and its major strategies of self-knowledge, rooted in systems of difference and otherness. But even more importantly, it serves to justify and validate the continued, genocidal indifference to the long-term consequences of HIV infection in any population group other than white, western heterosexuals. It is here that we can map out the complex relations between racial and sexual boundaries which legitimate and make possible the casual contemplation of the virtual extinction of all black Africans and all gay men.

Simon Watney⁶⁷

In his essay “AIDS, Language and the Third World”, Simon Watney draws attention to how discursive constructions of AIDS and of Africa intersect and combine to “permit a two-way ideological traffic between an unhygienic Africa, imagined as the original cesspool of disease, and an equally unhygienic homosexuality, similarly understood as a ‘natural’ source of contagion – both medically and sexually ‘unhealthy’” (1989:37). The term “African AIDS” appeared in the early years of the epidemic in media reports in the west about the growing crisis of AIDS in Africa. The concept was soon in common use and implied not only that there was something specific about AIDS in Africa, but, like the terms “French wine” or “Swiss chocolate”, that Africa was the source of AIDS. The discursive and material violence of the construction “African AIDS” has been subject to incisive critique by cultural theorists such as Cindy Patton, Paula Treichler and Simon Watney.⁶⁸ In spite of their work, the discourse of “African AIDS”, within which the pandemic is figured variously as a natural disaster, a catastrophe of apocalyptic proportion, and as signifying the demise of the continent of Africa itself, continues to be the primary mode of representing HIV and AIDS in Africa in the mainstream media in the west.

Central to the discursive construction of “African AIDS” are photographic images of people living with HIV and AIDS. I argue here that the use of images of the bodies of

⁶⁷ Watney (1994:110-111).

⁶⁸ For important early critiques of representations of AIDS in Africa see Patton (1990), Treichler (1989) and Watney (1992).

dying and dead Africans as the locus of “African AIDS” has played a critical part in the formation of what Watney has termed “genocidal indifference”(1994:110) to the plight of people living with HIV and AIDS in Africa. Through close readings of six archetypal images that claim to represent AIDS in Africa, I seek to decipher how a long, racist historical iconography has constructed Africa as a space of dying and death. In order to do this I follow Barthes’ directive, to try to establish the code of connotation that makes possible the reading of an image and that constitutes its meaning. His analysis of how photographic images can be read shows that practices of interpretation must themselves be historicized and interpreted. What does one see when one looks at an image of an African person dying of AIDS? What are the codes of connotation that enable us to recognize the image, to decipher its meaning?

Watney argues that within the discourse of “African AIDS”, Africa features as “not so much a geographical as an ideological location, hence its distinctive vagueness, making the epidemic ‘knowable’ in terms of a long racist legacy of colonial connotations of supposed depravity, dirt and disease” (1989:37). One of the most glaring recent examples of the ideological force of “African AIDS” is the *Time* magazine special report (see *Figure 1*) “AIDS in Africa: A Continent’s Curse” (*Time*, February 12, 2001). The feature consists of James Nachtwey’s photo-essay, “Crimes Against Humanity”, an article by Johanna McGeary, “Death Stalks a Continent”, described as “an in-depth examination of why AIDS has taken such a terrible toll in Southern Africa”, and finally, a brief “guide to some easy and inexpensive ways readers can make a difference in Africa’s battle against HIV” (*Time*, 2001:1).

Of the six black and white photographs depicting the HIV and AIDS epidemic in “Africa” that constitute “Crimes Against Humanity”, three are portraits of emaciated, dying people.⁶⁹ In each of these images the person depicted is only partially clothed and does not appear to be aware of being photographed. No-one depicted is named. Although entitled “Crimes against Humanity”, the photographs that make up the essay and the captions that accompany them provide no indication of who might be considered responsible for the ceaseless suffering and deaths the essay depicts. The lack of reference

⁶⁹ While the photo-essay ostensibly represents “AIDS in Africa” only two countries on the continent, Zimbabwe and South Africa, are featured.

to the multiple social, political and economic causes for the crisis of AIDS in Africa, including the omission of the role played by the west in the continuing exploitation and impoverishment of the continent, leads the viewer to speculate on what it is these poor dying souls have done to deserve such a ghastly fate. On the far left of the first image in the series, beneath the title of the essay, are the following words: "Even as you read this, AIDS is taking lives in sub-Saharan Africa, swallowing families, communities, hopes. So far 17 million have died. At least 25 million may follow. An intimate look at a modern curse" (2001:40). The suffering and premature deaths of HIV-positive Africans are described as inevitable and AIDS itself is imbued with a monstrous agency, "taking lives" and "swallowing families, communities, hopes" (2001:40).

The images are described as "An intimate look at a modern curse" and the essay itself is subtitled, "AIDS in Africa: Scenes from the Plague". The use of the words "curse" and "plague" serve to obfuscate the causes of the pandemic and erase all traces of human agency, implying instead that HIV and AIDS in Africa is an inexplicable tragedy. "Africa can provide no treatment for those with AIDS" (2001:47), McGeary's article baldly states, highlighting the tragic dimensions of the "AIDS plague" (2001:54) and depicting the epidemic as a "premodern medical catastrophe" (Watney, 1994:259). McGeary's description of AIDS as an uncontrollable plague obscures the existence of anti-retroviral therapy that has transformed HIV and AIDS into a chronic manageable condition in the west.

Metaphors of plague have long been one of the primary means of concealing the social causes of disasters in Africa, such as famine and other diseases, like malaria and tuberculosis, which although can be treated, claim the lives of hundreds of thousands of people each year. In her essay "Constitutional Symptoms", Jan Zita Grover writes of the part played by metaphoric language in determining how society responds to public health issues:

As Sontag has pointed out, cancer has been popularly and medically metaphorized as a *war*, replete with battles, skirmishes, victims and heroes. The usefulness of this metaphor in describing the unknown may account for its common usage; we have not only war on cancer, but wars on drugs, wars on crime, wars on juvenile delinquency, wars on hypertension, wars on sickle-cell anaemia, wars on mental illness. So commonplace, in fact, is the conceit of war in discussions/actions on

issues of public concern that its *absence* in the case of AIDS becomes a particularly signifying absence or silence. (Grover, 1989:153)

While Sontag argues against the use of metaphor in representing disease, Grover points to what she terms “the necessity of metaphor”. Rather than calling for the eradication of metaphor (which in any case Grover understands to be impossible), she asks, “What does it mean not to have AIDS constructed in terms of ‘a war against ...’? What metaphors have been used instead, and what are the significances of their use?” (1989:153). She goes on to note how the primary metaphor used to speak about HIV and AIDS is that of contamination, which unlike the metaphor of war, aims to separate those who are infected from those who are not. In “Powers of Observation: AIDS and the Writing of History”, Watney critiques the “ideological operation” of the use of plague metaphors in the discourses of HIV and AIDS within which “the epidemic is casually naturalised, made to seem inevitable, and all sense of human agency, or injustice, or ethical responsibilities, neatly and conveniently disappears” (1994:262). Besides the fact that metaphors of plague invoke biblical notions of judgement and punishment, Watney observes that such metaphors “are singularly misleading and inappropriate in relation to AIDS for the simple reason that unlike the Black Death or cholera, HIV is *not* contagious” (1994: 259). In spite of the fact that HIV cannot be “caught” and can only be transmitted through sexual intercourse, the exchange of blood and from mother to child, those who are infected with HIV are identified as a threat to the bodily integrity and well being of others. As Ross Chambers observes, the weakened immune systems of people living with HIV and AIDS means that “What the PWA [Person with AIDS] has most to fear is infection – which is why it is both ironic and cruel that AIDS patients are treated, both medically (with all the apparatus of gowns, masks and gloves) and socially (they are shunned), as if they were *themselves* dangerously contagious” (Chambers, 1998:24-5).

The term “plague” implies that addressing the crisis of AIDS in Africa is beyond the powers of human intervention and the global political and economic factors that determine access to essential medicines are rendered inconsequential. In *Infections and Inequalities* Paul Farmer writes that, “ensuring equal access to effective medical interventions can efface the biological expressions of social inequalities” (Farmer, 1999:266). At the same time he observes that despite the existence of effective treatment

for HIV and AIDS, it is unlikely that the majority of those who need these drugs will receive them:

In the developing world, where the majority of potential beneficiaries [of anti-retroviral therapy] live, virtually no one is receiving, or is even slated to receive, the new drugs. Protease inhibitors, we're told, are not "appropriate technology" for the residents of poor countries. (Farmer, 1999: 267)

The use of black and white film in the images that constitute "Crimes Against Humanity", the only images in the publication that do not appear in colour, contributes to the sense that people living with HIV and AIDS in Africa occupy a place outside of western modernity and outside of the reach of medical care. This notion is reinforced by the way in which Nachtwey's photo-essay is positioned, immediately after an article on the World Economic Forum meeting in Davos, illustrated by photographs of five white businessmen and policy analysts dressed in expensive suits.

The contrast between the photographs of "Time's Board of Economists", all depicted standing upright and in the act of speech, and the photograph that follows overleaf of the emaciated body of a black woman being lifted from her wheelchair, her head bent backwards and her mouth open, full of teeth and empty of words, is marked. Each of the images of the economists incorporates a caption printed alongside the respective person or overlaid on their body that conveys their perspectives on the new global economic order, their names and their institutional affiliation. The photograph of the dying woman being lifted from her wheelchair (Image One, *Figure 2*) bears the following caption: "Last Trip: A 28-year-old woman leaves her three children to enter a home for dying AIDS patients". The dying woman is framed on either side by the two women who are dressed in uniform and are shown attempting to lift her body from the chair. The faces of the two women, evidently nurses or hospice workers, are not visible. At the centre of the image is the skeletal hand of the dying woman resting against the arm of the wheelchair and just beyond it, her wasted abdomen and chest, one of her collapsed breasts exposed as her shirt is raised towards her shoulders by the woman who appears to be wrenching her out of her wheelchair by her shoulders. The woman's pain is palpable and awful to behold. Her head seems too great a burden for her frail neck and her eyes and teeth appear enlarged, her stare desperate. It is her eyes and her mouth that draw the viewer's gaze, with horrifying effect. Her own gaze is directed upwards, not at the face of

the nurse who is lifting her but through her, beyond her, a beseeching stare. The decision to begin the sequence of images with this double-page spread, one that issues a plea for assistance as it simultaneously casts sick and dying Africans out of time and beyond saving, sets up the rhetorical strategy that structures the entire feature.

Image Two, a half page medium shot that portrays an extremely ill man, dressed only in his underwear, the skin on his face, shoulders and arms covered in lesions (see *Figure 3*). The man holds his arms away from his body in an awkward pose, as if it is too painful for the skin on his arms to come into contact with his body. On the right hand side of the image a clothed arm extends into the frame, the hand gloved and holding an instrument with a ball of cotton-wool at its end to the face of the sick man. “Helping Hand: At this Zimbabwe hospice, all the caregivers are themselves HIV-positive. Here, a patient has his lesions gently medicated”, the caption reads. As in the photograph of the dying woman in the wheelchair that precedes this image, it is the face and eyes of the sick man that draw the viewer’s gaze. But just as in the first image the man does not meet the viewer’s eyes but stares into the distance, and as before, the subject of the image is not named.

Photography has been a tool of empire as well as a tool of medical science, both epistemes based on the power of the gaze, the coincidence of vision and knowledge and the conjunction of knowledge and power.⁷⁰ The images I discuss in this chapter speak of the power that lies in being able to look without being looked at and also indicate how vulnerability and exposure are bound.

Image Three bears the following caption: “Long Walk: A sick man leaves the shower in a Harare hospital. Soon nurses will have to clean him. Dignity is one of AIDS’ first casualties” (2001:42). The image shows the emaciated frame of a man, photographed from behind, his arm outstretched, his hand against the wall to support him (see *Figure 3*). The man is draped in a dark cloth, perhaps a towel or blanket that falls over his arm like a bat’s wing. On the white-tiled wall his ghostly reflection hovers. The door of the shower is visible in the foreground and two of its glass panels are cracked. These small signs of disrepair construct the space of the hospital as one of death and decay rather than

⁷⁰ See Anne McClintock’s interesting discussion of photography and empire in her *Imperial Leather* (McClintock, 1995:122-126).

of high-tech medical miracles.⁷¹ The caption, which includes the statement, “Dignity is one of AIDS’ first casualties”, implies that to become sick with AIDS and to require medical care is undignified. While it is the ways in which people living with HIV and AIDS are treated by others that determines whether or not they are stripped of their dignity, AIDS is again personified here. Resting the blame for the ways in which people living with HIV and AIDS are suffering on the “AIDS Plague” is to divert attention from the social causes of the epidemic, among these, how people living with HIV and AIDS are represented.

The next two images (Images Four and Five) are of young people and are presumably intended to provide a glimpse into the future of the epidemic. Image Four, a close up of “authenticated Zulu virgins at a testing ceremony in rural South Africa”, their heads marked with supermarket stickers to signify their virginity, could offer insight into local responses to the epidemic (see *Figure 4*). Taken out of context and positioned next to images of dying bodies, the photograph reads only as bizarre, a strange cultural spectacle that affirms the distance between those depicted and the readers of *Time*.

This image is distinct from the other photographs that make up the essay in that it does not show the bodies of the young women it portrays. The closely cropped image shows the heads of seven girls, six of whose eyes are visible. Besides the gaze of the young woman in the foreground which is directed into the distance, the eyes of the five other girls whose faces are visible are looking directly at the viewer. None of the girls is smiling and the expression in their eyes could be construed as hostile. Like Image Five, a portrait of street children in Harare, this image does not arouse the viewer’s sympathy or identification.

Image Five is captioned as follows: “Street Life: Boys living on a Harare corner. Many lost both parents to AIDS; some have lost one and been rejected by a step-parent” (2001:43). The focus is provided by the three boys in the foreground, two sitting and one crouching on a dirty pavement (see *Figure 4*). There are ten other street children who enter the frame, six shown asleep under blankets in the background, parts of the bodies of the four remaining boys forming a circle with the three boys whose faces are visible at

⁷¹ In the following chapter I explore how hospitals in Africa are represented as spaces of death in greater depth through my analysis of a series of images, also of patients in a hospital in Zimbabwe, by Gideon Mendel.

the centre. The boys are dirty, dressed in ragged, torn clothes, with bare feet or broken shoes. The boy on the far left of the image is holding the edge of a small packet of milk in his mouth but does not appear to be drinking. His head has been elongated by the angle of the photograph and his face and eyes are distorted. In the middle is a boy with his knees pressed against his chest, his hands outstretched before him as if searching through the debris on the ground for tobacco, or perhaps to conceal something. His head is turned up and the camera looks down on him, his wide eyes an echo of the beseeching stare of the dying woman who appears on the preceding page. The boy next to him holds a cigarette, a trail of smoke emerges from his mouth, and he too directs his gaze upwards. These boys, like the “virgins” depicted in Image Four, are reduced to examples of the effects of AIDS in Africa, their individual subjectivity subsumed by the way they are categorised as members of “risk groups”. McGeary’s “Death Stalks a Continent” follows this pattern – the article is structured through sections that take the experiences of individuals as exemplary – “The TB Patient”, “The Outcast”, “The Truck Driver”, “The Prostitute” and “The Child in No. 17 [crib]” (53).

The final image in Nachtwey’s photo-essay (Image Six) depicts a man wearing a mask and gloves, standing behind a canvas cover he has lifted up to expose the corpse of a woman, her body wrapped in a white sheet, her feet and her face exposed. The caption reads: “Final Rest: A young woman wrapped and awaiting burial at a Harare hospital. The funerals add a sad regular rhythm to African life.” The woman’s body has been laid out on a metal gurney and her corpse extends across two pages, cut in the middle by the vertical line formed where the pages join. Part of her face is in shadow and a thin line of darkness crosses her eye. A small distance from her head is a slip of paper, another appears at her feet. Both are illegible. The piece of paper at her feet is recognisable as an official form, the words “Deceased Patient Card” appear faintly but the information it contains, presumably the person’s personal details, are indistinguishable.

The inclusion of this image of an unnamed dead woman photographed in a hospital raises a series of questions about the ethics of the journalistic and editorial practices that determine how people in the developing world are depicted. While it seems unlikely that informed consent was obtained from any of the living subjects depicted in the photo-essay, it is clearly not possible to obtain permission from the dead. While it is possible

that the photographer obtained permission from the deceased woman's family, this too seems unlikely. Depicted without either her name or any sense of the context in which she lived, this woman's body comes to stand in for deaths other than her own. The forms of erasure to which she is made subject raise further questions still about the relation between representation and dehumanisation and about how certain lives are afforded value while others are not. Her death is an instance of what Judith Butler has termed, "unmarkable and ungrievable", a life and death that has not been recognised as occupying a place within the bounds of what constitutes the human:

The matter is not a simple one, for, if a life is not grievable, it is not quite a life; it does not qualify as a life and is not worth a note. It is already the unburied, if not the unburiable. It is not simply, then, that there is a "discourse" of dehumanisation that produces these effects, but rather that there is a limit to discourse that establishes the limits of human intelligibility. It is not just that such a death is poorly marked, but that it is unmarkable. Such a death vanishes, not into explicit discourse, but in the ellipses by which public discourse proceeds. (2004:34-35)

The photograph of the unnamed corpse makes visible the dead body of the unnamed woman at the same time as it marks the disappearance of the subject of that body. This image, like the photograph of the woman being lifted from her wheelchair, extends across two pages. It is interesting to consider why it has been accorded so much space, and even why it has been included at all. In the section that follows I suggest that the bodies of Africans have come to be the locus not only of AIDS but of also of death. The appearance of their dying and dead bodies serve to reassure those who view them that the spaces of death are elsewhere, on the other side of the invisible boundary that separates the living from those who are living in the mode of dying.

Photographic Analgesia

Protected middle-class inhabitants of the more affluent corners of the world – those regions where most photographs are taken and consumed – learn about the world's horrors mainly through the camera: photographs can and do distress. But the aestheticizing tendency of photography is such that the medium which conveys distress ends by neutralizing it. Cameras miniaturize experience, transform history into spectacle. As much as they create sympathy, photographs cut sympathy, distance the emotions. Photography's realism creates a confusion about the real which is (in the long run) analgesic morally as well as (both in the long and in the short run) sensorially stimulating.

Susan Sontag⁷²

Increasingly the divide between the first and third worlds can be mapped out through vastly different experiences of embodiment. This is not to say that no one any longer dies in the west, but that a distinction can be drawn between how the majority of people live there, and how and when they die, and how people live and die in other places. There is also a distinction that can be drawn between what these differently embodied lives and deaths come to mean.⁷³ For instance, in the same issue of *Time* that Nachtwey's photo-essay appears is an article on the Lockerbie air disaster court case, the verdict on which had just been passed. The article describes how there are several memorials for the victims of the explosion in Lockerbie itself:

For the dead there are discreet memorials all around. In the cemetery, a plain slab of gray Aberdeen granite bears all the victims' names. In Tundergarth churchyard, 5km away and opposite the field where the plane's blue-and-white nose fell, a tiny stone building houses two memorial books. One lists the dead in flowing script, another records their personal histories. Pilgrims who come to this silent, haunting place have also left signed photographs behind, mostly of children, or notes in the visitor's book. "John Michael Ahern. RIP. Always in our hearts. Love, Dad," was one poignant entry last month for the 26-year-old from New York who loved skiing. (2001:27)

Consider how differently McGearry approaches the deaths of people living with HIV and AIDS in Africa just twenty pages on:

Flesh and muscle melt from the bones of the sick in packed hospital wards and lonely bush kraals. Corpses stack up in morgues until those on top crush the identity

⁷² Sontag (1973:109-110).

⁷³ In this regard see Butler (2004) and Simpson (2006).

from the faces underneath. Raw earth mounds scar the landscape, grave after grave without name or number. (2001: 47)

This grotesque vision is also an imaginary one. In McGeary's article and in Nachtwey's photographs, the stories of people living with HIV and AIDS in Africa are subsumed by the singular non-story of "African AIDS", one of endless, generalised suffering detached from the specificities of any individual life. Each unnamed, emaciated African body is made indistinguishable from those dying of starvation, or those dying in refugee camps, or those dying in war-torn places. Resonances of the long history of what might be termed "colonial codes of connotation" are evident in constructions of Africa as a space of disease and death today. It is in this sense that Barthes' contention that the primary function of photographic connotation is to reassure the viewer can be understood in relation to images of dying and dead African people. Such images reassure those who view them that the global order remains as they know it to be: the lives of people in the west are protected while those outside of the west may be exposed to death at any time.

Barthes argues that photographs convert trauma into something that can be witnessed at a distance. For him a traumatic image is one that cannot be described, an image about which there is nothing that can be said:

The trauma is a suspension of language, a blocking of meaning. Certainly situations which are normally traumatic can be seized in a process of photographic signification but then precisely they are indicated by a rhetorical code which distances, sublimates and pacifies them. Truly traumatic photographs are rare, for in photography the trauma is wholly dependent on the certainty that the scene 'really' happened: *the photographer had to be there* (the mythical definition of denotation). Assuming this, which in fact is already a connotation) the traumatic photograph (fires, shipwrecks, catastrophes, violent deaths, all captured from 'life as lived') is the photograph about which there is nothing to say; the shock-photo is by structure insignificant: no value, no knowledge, at the limit no verbal categorization can have a hold on the process instituting the signification. (1977: 30-31)

On the 11th of September 2001 viewers around the world were witness to an image of an aeroplane crashing into the World Trade Centre and of the Twin Towers falling, killing those inside the building and many people on the New York streets below. The image had horrifying force because in a world in which images of disaster and death in spaces outside of the west are in perpetual circulation, this particular sight was an anomaly. This

perhaps also accounts for why the image was infinitely replayed and reprinted – the scene had to become familiar in order for its traumatic effect to be diminished.

While repetition may lessen the degree to which viewers are affected by traumatic images, repetition does not diminish trauma but instead compounds it. In the section that follows I read an image that indicates how the objectification, exposure and public display of the bodies of black women over several centuries persists in the present and perpetuates the material violence to which black women are subject.

Disrupting visual codes

The camera has often been a baleful instrument. In Africa, it arrived as colonial paraphernalia, along with the gun and the Bible. As it recorded the exotic and profound, the camera altered reality, introducing new impulses and confessions, cataloguing the converted and the hanged. The photograph often captured the most loaded fraction of time, calcifying an unequal, brutal and undemocratic human encounter.

Yvonne Vera⁷⁴

In their collection *Mwendanjangula! AIDS in Zambia*, Dutch journalist Arthur van Amerongen and photographer Geert van Kesteren seek to portray the immense suffering that the epidemic has brought about in Zambia. Their project, and the publication of their book, was funded by several international aid organisations, the Stichting AIDS Fonds, HIVOS, ICCO, the Mondrian Foundation and Unicef. Van Amerongen is a well established journalist in Holland and Van Kesteren was acclaimed Dutch Photojournalist of the Year in 1998. Their book contains images of people in mourning and at prayer as well as photographs taken inside hospitals, brothels and mortuaries. The book also includes a textual account of their journey through Zambia with Clement Mufuzi, a Zambian AIDS activist. While a fair amount of detail about Mufuzi's life is given in the text, the stories of the lives of most of the other people depicted are not told. Almost all of the 72 black and white images in the collection are of people and most are

⁷⁴ Vera (2000:232)

accompanied not by the name of the person photographed but instead by a place-name that indicates where the photograph was taken. The absence of names and of narratives that would provide context for these portraits reduces individual lives to instances of “Zambian AIDS” (see *Figure 5*).

Disregard for the privacy of both men and women living with HIV and AIDS characterises the images in both *Mwendanjangula!* and *Time’s* photo-essay, but in each instance the bodies of women are exposed in ways that the bodies of men are not. In *The Feminization of Famine* Margaret Kelleher observes that in contemporary representations of famine “the nakedness of women is a frequent and particularly troubling feature” and that “voyeuristic and intrusive famine spectacles [...] create a dangerous configuration of issues of sexuality and charity” (Kelleher, 1997:228). In the following section I read two images included in *Mwendanjangula!* that are disturbing for the unequal relations of power they reveal.

Image One bears the caption “Dr. David Koetsier, tropical-medicine specialist, at the Kaoma District Hospital, Kaoma, 1999”. Koetsier, a white Dutch doctor, is shown crouching at the bedside of a female patient. Her blanketed body stretches across the right hand side of the image and her arm extends outwards towards Koetsier. In the palm of her hand is something white, a balled-up tissue or piece of cotton-wool. The doctor appears troubled, his eyes bear a worried expression behind his glasses, one of his hands is raised to his head.

Image Two is captioned, “Kaoma District Hospital, Kaoma, 1999”. The photograph shows the naked body of a young black woman, her legs spread apart and in stirrups, her breasts exposed and her eyes shut, a pose that could be mistaken for sexual pleasure. Beneath her raised calf and alongside her thigh, the same doctor who appeared in the previous image is visible. He is shown examining her vagina or performing a surgical procedure on her genitals. The invasiveness of this image, and in particular the way in which the woman’s body is eroticised, makes it extremely discomfiting to view.

Although her body is entirely exposed, the woman is not identified and no mention is made of her story in the text that accompanies the photographs in the book. The story behind the image, the story of a woman living in rural Zambia where she may have waited weeks, even months, for access to medical care, remains undocumented. The

appearance of this image relies on the absence of narrative; it is this untold story of both local and global political and socio-economic inequality that makes possible its existence and sanctions its circulation.

I cannot be certain whether or not the photographer obtained consent from this woman to be photographed, but even if he had asked her permission, it is difficult to imagine how it would have been possible for her to refuse. In the contemporary context where the right to both medical treatment and privacy are the preserve of the wealthy, this woman's right to assert what should become of her own body has been taken from her. The viewer's gaze can fall upon her body, can be scandalised and can consume her, without ever recognising her as human at all.

In *Mwendanjangula!* and in the *Time* photo-essay, the stories of people living with HIV and dying of AIDS in Africa are subsumed by the singular non-story of "African AIDS", a litany of endless suffering that is not thought to *belong to them*. Theirs' is a suffering that precedes them and that will continue after their deaths; a suffering that is ceaseless and that has come to assume the status of the natural. Such discursive constructions place under erasure the political and economic factors that determine which of the world's people have access to medical treatment and which do not. Yet the growing divide between the rich and the poor is everywhere in evidence and is made plain in the final section of *Time's* feature on AIDS in Africa.

The last page of "Death Stalks a Continent" is devoted to ways in which the reader of *Time* can make online donations to a variety of projects focusing on prevention, care of orphans, training of home-based carers and small business start-up loans. It is striking that no mention is made of anti-retroviral therapy, the only existing treatment for AIDS that can reduce mortality and fundamentally change the course of the epidemic. Acknowledging the efficacy of anti-retroviral drugs and the dire need for generic drugs to be produced in order to make such treatment widely accessible leads to the question of why such treatment has not been made available to those who require it. And in turn, this necessitates engaging with how governments and multi-national pharmaceutical companies have colluded to protect their financial interests and have turned a blind eye to the suffering of millions. The cumulative effect of the images I have analysed in this chapter is an insistence upon the inevitability of the deaths of people living with HIV and

AIDS in Africa which, *Time's* photo-essay asserts, "add a sad and regular rhythm to African life". These forms of representation that engage in a fatalistic politics of doom do little to alleviate the suffering of those they claim to represent. Instead they more often work to compound that suffering through the production of hopelessness and despair.

If, as Barthes asserts, representation converts traumatic experience into that which can be witnessed and is thereby neutralised, how can traumatic events and experiences be representing without anesthetizing the viewer? In her book *The Emptiness of the Image*, psychoanalytic theorist Parveen Adams reads a photograph by artist Della Grace of three women, naked but for their jackboots, standing in the pose of the Three Graces, their arms around one another and their heads shaved. Adams' reading of the image is equally provocative. She writes: "These women are beyond recognition. For it is within the realm of recognition that the representation of women is played out" (Adams, 1996:123) And indeed, one could argue that all representation is played out in the realm of recognition. For in the act of looking at a photograph the viewer "reads" the image in a manner that Barthes describes as "always historical" (Barthes, 1977:28). If images are always overdetermined by their history, caught in a discursive web with no beginning and no end, how can representations shift?

Recognition is a process that may be looked at from two sides. Women who are recognized as such are recognized by a rigorous template of definition. If we do not recognize, in this photograph, these women, it is not because they are recognized as something else. It is rather because the structure of recognition has been suspended. (Adams, 1996:138)

Adams' analysis offers a way to think through the possibility that the history of the image can be confounded. The importance of the possibility for the suspension of the structure of recognition and the disruption of visual codes becomes clear when one considers how codes of connotation work to neutralize the unfamiliar and convert traumatic experience and suffering into spectacle. If what one sees when one looks at an image is the history of that image in an instant, to be beyond recognition is to be unencumbered by history. But what does it mean to be beyond recognition? Is being beyond recognition equivalent to being unrecognised? How does being beyond recognition open or close the field of political possibility?

In the following chapter I argue that photography's power lies in those aspects of images that are least easily translated and in its potential to produce images that confound the structures of recognition. At the same time I argue that a particular kind of recognition is critical in attaining access to political representation. I draw attention to how visual representations of people living with HIV and AIDS have shifted in Southern Africa as treatment activists have claimed their right to political representation. In my analysis of the work of Gideon Mendel I show how images of dying Africans have been superseded in his oeuvre by a series of portraits that resemble passport photographs. I argue that this shift is significant in that it confounds the codes of representation through which Africans have been cast always and only as dying, and marks their claim to being recognised as living subjects by society and by the state.

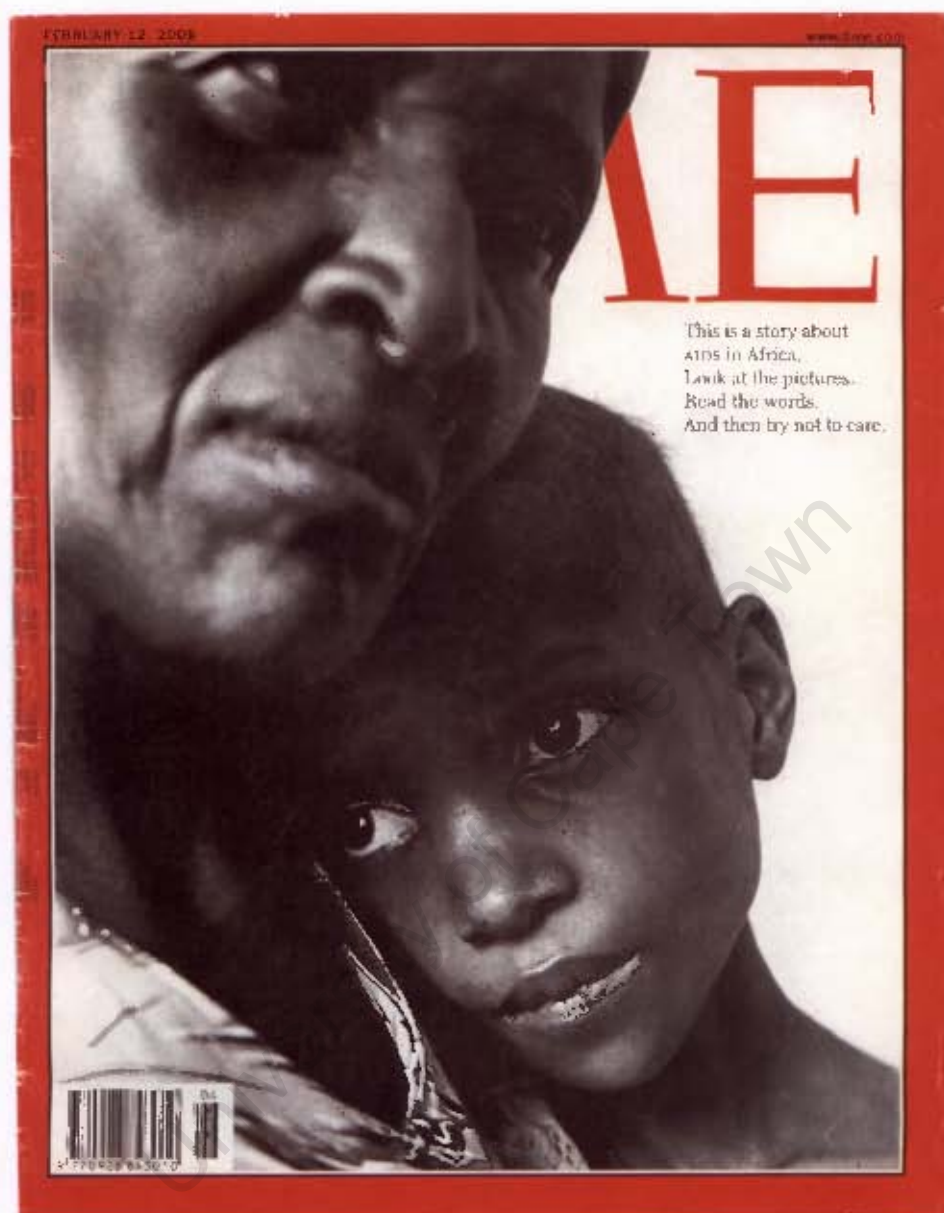


Figure 1



Crimes Against Humanity

Even as you read this, AIDS is taking lives in sub-Saharan Africa, devastating families, communities, hopes. So far 17 million have died. At least 17 million may follow, its patients lack of a modern cure.

Photograph for TIME by Sam McCracy—Mogum

Figure 2

AIDS IN AFRICA Scenes from the Plague



MS. FONG HUND: At this Zimbabwe hospice, all the caregivers are themselves HIV positive. Here, a patient has his lesions gently medicated



LONG WALK: A sick man leaves the shower in a Harare "hospital. Soon nurses will have to clean him. Dignity is one of AIDS' first casualties

Figure 3



CERTIFIED: Supermarket stickers are used to mark the heads of authenticated Zulu virgins at a testing ceremony in rural South Africa



SPECTER OF: Boys live in a Harare cancer. Many lost both parents to AIDS; some have lost one and been rejected by a step-parent

Figure 4



Figure 5

Chapter Four

Photography and (Dis)appearance

In the previous chapter I argued that through the discourse of “African AIDS” Africa figures in the global imaginary as a space of death. The specificity of the experiences of people living with HIV and AIDS in Africa are lost; those depicted are often unnamed, their individual lives made unrecognisable. In this chapter the photographs I analyse avoid many of the crudely homogenising and dehumanising effects I drew attention to in Chapter Three. I argue that although the images I discuss here do not enact the same forms of discursive erasure as those I have identified as instances of “African AIDS”, they nonetheless remain enmeshed in a connotative structure that permits only a particular form of visibility.

This chapter takes as its focus the photographic images of people living with HIV and AIDS by Gideon Mendel, a London-based South African photojournalist. Mendel, who began documenting the epidemic in 1993, is one of a small group of photographers who have engaged with the issue of HIV and AIDS over time.⁷⁵ His body of work provides the most significant photographic record of the effects of the epidemic in Sub-Saharan Africa, and South Africa in particular.⁷⁶ *A Broken Landscape* (Mendel, 2001), chronicles the impact of HIV and AIDS on everyday life in Malawi, South Africa,

⁷⁵ See the work of Jane Evelyn Atwood whose photograph of “Jean Louis” appeared in *Paris Match* in 1987 and was the first publicly circulated image of a person living with AIDS in France. Maggie Steiber and JB Diederich photographed people living with HIV and AIDS in Haiti and in the United States, Alon Reininger, Dilip Mehta (who photographed Ryan White), Nan Goldin and Frank Fournier were among the first photographers to document the epidemic. Reininger was also one of the first photojournalists to photograph people living with HIV and AIDS in Southern Africa. Others to have worked in the region include James Nachtwey, Nick Danziger, Don McCullin, David Chancellor and Kristen Ashburn. See also Jeffrey Barbee’s images of people living with HIV and AIDS in Swaziland and the work of Jide Adeniyi-Jones in Nigeria.

⁷⁶ Mendel won the W. Eugene Smith Grant in Humanistic Photography in 1996. His photographs depicting people living with HIV and AIDS in Africa have been exhibited across the world. His work appeared in *National Geographic* (September 2005) and often appears in the English newspaper, *The Guardian*.

Tanzania, Zambia and Zimbabwe. A selection of photographs from the book were exhibited at the National Gallery in Cape Town from January to April that same year, and during that time Mendel began work on a new series of photographs focusing on access to anti-retroviral therapy in South Africa. Through an analysis of this body of work it is possible to trace how “AIDS”, and more recently “HIV”, has been imagined and represented. In particular, Mendel’s work shows how the emergence of an HIV and AIDS activist movement and access to anti-retroviral treatment in South Africa has led to new forms of representation of HIV-positive subjectivity.

In the first section of this chapter I analyse two image sequences drawn from *A Broken Landscape*: “Mission Hospital, Matibi, Zimbabwe” and “Mzokhona Malevu, Enseleni Township, South Africa”. I then turn to an analysis of Mendel’s portraits of people who have access to anti-retroviral therapy. I argue that there is a marked shift in Mendel’s practice which is evident in these new images and which both shapes and reflects changing perceptions of the epidemic and of people living with HIV and AIDS in South Africa. In the final section of the chapter I consider Mendel’s increasingly extensive use of testimony in his work and try to think through what this shift in his practice signifies. I argue that narrative has increasingly come to be attached to images that represent people living with HIV and AIDS in Africa as a way to secure photography’s claim to authenticity and to representing the truth of its subjects. Rather than arguing for increasingly transparent representations that reveal the “truth” of AIDS, I consider how that which resists the interpreting gaze might serve to open the question of how AIDS might be imagined otherwise.

Photography and AIDS

Within the popular media, photography has played a central role in how AIDS in Africa has come to be imagined and known.⁷⁷ It has been through photographic images of

⁷⁷ I refer here to the ways in which AIDS has been visualised rather than HIV *and* AIDS, as representations of people living with HIV, with a few notable exceptions, have only recently begun to emerge. The shift towards documenting people living with HIV *and* AIDS in the Southern African context forms part of the focus of this chapter.

people living with, and mostly dying of, AIDS, that AIDS in Africa has come to figure in the cultural imaginary. As I have argued in the preceding chapter, the imagined locus of “AIDS” moved from gay, mainly white bodies in the early years of the epidemic, to the bodies of black Haitians, and then to black Africans. The bodies that have come to signify “AIDS” are now primarily black African bodies and the global pandemic is pictured as African. In this chapter I examine some of the implications of the production and circulation of photographs of African bodies within the global economy of images. Before I turn to an analysis of the effects of photography on people living with HIV and AIDS, I wish to consider how AIDS has affected photography.

In June 2001 the online journal *The Digital Journalist* released a special issue commemorating photography’s role in documenting the epidemic over the course of twenty years. The issue includes interviews with many of the leading photographers in the field as well as reproductions of images that provide fascinating insight into how photography has shaped public perception of HIV and AIDS. Mendel is one of several photographers who relate how their work has in turn been shaped by the epidemic:

In 1993, I was part of a group project called “Positive Lives,” organized by my photo agency, Network, in which photographers responded to AIDS in the U.K. My first exposure to the issue was photographing in an AIDS ward in London. I found the situation different than any I’d ever experienced as a photojournalist. It was only 10 percent photography and 90 percent communication and connection with people, dealing with issues of confidentiality, considering how people should be projected, being sensitive not to portray people as victims. That same year, I made contact with a mission hospital in Zimbabwe and I photographed there. I felt that as an African photographer I needed to find a way to respond to the AIDS crisis which was clearly developing in Africa at that time. So that essay, looking at one remote hospital in an area where more than 25 percent of pregnant women were testing HIV-positive, was the beginning of my work on HIV and AIDS in Africa. (Mendel, 2001)

In his statement Mendel draws attention to how photographing AIDS presented a new and unique “situation” for photography, one that led to a shift in his practice. In photographing AIDS, Mendel suggests, a series of issues arise that complicate the process/act of representation: the need to maintain confidentiality, the need for an awareness of what the effects of the image might be, and recognition of the ideological force of the re-inscription of generic conventions. Why Mendel would perceive these problems as related to photographing AIDS in particular is something I take up in the

sections that follow. Here I consider how AIDS has been read as that which cannot easily be made visible, commodified and aestheticised, and as that which exceeds representation. An interview in the same issue of *The Digital Journalist* with leading photojournalist Don McCullin serves to amplify Mendel's concerns with the challenges involved in representing AIDS.⁷⁸ McCullin describes the problems AIDS poses for photography in the following way:

In terms of photojournalism, the AIDS issue has an enormous problem. It has to appear in print. Yet it's so visually unkind to the eye. It infringes upon the comforts of magazines themselves because it's difficult for the business side to run advertising up against certain serious stories, and AIDS is one of the most unattractive, powerful and important visual stories on earth. AIDS is the biggest human story on the globe at the moment. To give it prominence, we have to give it public hearing. But magazines are showing intolerance now because they're saying, 'Well, we've done that. We did that last year.' The problem is, AIDS will go away from our imaginations if editors and photographers and creative people don't constantly make it *appear*. (McCullin, 2001)

For photojournalism, McCullin states, the problem with AIDS is less its appearance than that it continually threatens to disappear.⁷⁹ "AIDS" circulates as a commodity, competing with wars, outbreaks of new diseases, natural disasters and humanitarian crises for place in the global imaginary. McCullin refers to the "editors and photographers and creative people" who make "AIDS" appear, drawing attention to how, in order to appear, "AIDS"

⁷⁸ Don McCullin was born in England in 1935. He is best known for his documentation of war in Cyprus, the Congo, Biafra, Vietnam, Cambodia and Iraq. In 2001 he travelled to Africa with Christian Aid to document the HIV and AIDS epidemic. This visit resulted in the exhibition "Cold Heaven: Don McCullin on AIDS in Africa" at the Whitechapel Art Gallery. A return journey to South Africa and Zambia in 2004 resulted in "Life Interrupted" which together with "Cold Heaven" has been widely shown in England. It is possible to view the images on the Christian Aid website: www.christian-aid.org.uk Selected images from "Life Interrupted" can also be seen on the BBC news site www.bbc.co.uk alongside Jane Elliot's article "Recording the African HIV tragedy" (24 November 2004).

⁷⁹ The disappearance of AIDS certainly would pose a threat to those whose livelihoods depend on documenting the epidemic and who are engaged in securing a place for AIDS in the popular imaginary. Included in the AIDS-industry are all those who take the misfortune of others as their object of knowledge and in some way profit by it. This would include those who are working to alleviate the crisis, medical scientists and practitioners, anthropologists, public health specialists, cultural theorists, photographers and students like myself. Of course, what McCullin means here is keeping AIDS in the public eye is important so that AIDS does not fall off the cultural and political radar. That people living in the Third World depend on being seen by the west for their continued existence is implicit in McCullin's humanitarian sentiment. This is an assumption that I place under question in this chapter and throughout this dissertation through my analysis of how the position of people living with HIV and AIDS in Africa has been overdetermined by western violence, both scopic and material. For people living with HIV and AIDS, those on the other side of the lens and who occupy those bodies and landscapes that McCullin terms "visually unkind", the ways in which AIDS has constantly been made to appear can be understood as a violent form of discursive erasure.

must be configured in a particular way. Images of people living with HIV and AIDS that appear in the media in the west must therefore be read in and through this restrictive discursive field which permits entry only to certain forms of representation.

In this chapter I consider a series of questions, provoked by McCullin's statement, in relation to Mendel's photographs of people living with HIV and AIDS in Africa: Through what configuration of discursive lenses is AIDS made visible? What is made visible and what, in turn, is made invisible through the ways in which AIDS is represented? What do we see in seeing AIDS? What if AIDS were to disappear "from our imaginations", at least in the form in which it currently appears? In the section that follows I read two image sequences drawn from *A Broken Landscape*: "Mission Hospital, Matibi, Zimbabwe", "Mzokhona Malevu, Enseleni Township, South Africa". My readings of these images are framed by three aspects that McCullin identifies as difficulties in the representation of AIDS: AIDS as commodity, AIDS as visual story, and the importance of public appearance. My analysis makes use of Barthes's influential approach to reading photographs in *Camera Lucida*, in particular his articulation of what he terms the *studium* and the *punctum*.

The Commodification of AIDS: "Mission Hospital, Matibi Zimbabwe"

I begin my analysis of Mendel's work by reading his first photographic essay representing AIDS in Africa, the images he took in Zimbabwe in 1993 at Matibi Mission Hospital. This series of images is included in *A Broken Landscape*, and is one of four sequences of images depicting hospital patients in the book. *A Broken Landscape* is 208 pages in length and contains 127 black and white photographs of people living with HIV and AIDS in Southern Africa. There are several "portraits" that are made up of a series of images of an individual living with HIV and AIDS and those who care for them. Each of these sequences is prefaced by an extended caption, either the words of the person depicted or of a family member and/or caregiver. With the exception of the sequence depicting Mzokhona Malevu, which I discuss below and which has three pages of text accompanying 17 images, all of the extended captions are between half to one page in

length. The sequences that depict hospital patients are distinguished from the other sequences in the book in that none of the individuals depicted are named, nor is text provided alongside the images relating the stories of those shown.

The caption that begins the Mission Hospital sequence is given as follows: “Mission Hospital. Matibi, Zimbabwe / A remote rural hospital in an area where nearly 30% of pregnant women test HIV positive” (32). What is of importance here is what is omitted from the caption. As noted above, unlike many of the other sections in the text, no names are given for those depicted nor is there any testimony or description of their lives. It is also interesting that while the caption draws attention to the high infection rates among pregnant women in the area, no visibly pregnant women are shown in the section that follows, or indeed, anywhere in the book. While the section begins with an image of two seated women, (Image One discussed below), and women feature in each of the eight images that constitute the sequence, they appear as caregivers to the men who are shown to be sick and dying. This sequence also provides a particularly striking instance of how what McCullin terms the “visually unkind” aspects of AIDS disturbs the contained world of consumer capitalism, “infring[ing] on the comforts of magazines” and by implication, the readers who choose whether or not to purchase them. Four of the eight images included in this sequence depict a man who is dying and whose death Mendel witnesses and photographs. I analyse the significance of the image of the instant of this unnamed man’s death (Image Eight) and the absence of text to provide an explanation for it below.

The Mission Hospital sequence shows conditions in the hospital compound and inside the hospital building (32-45). It begins with an image of two women sitting on a concrete structure, a square alcove that resembles a window-seat without a window (Image One, see *Figure 1*). The women are framed by a concrete wall behind them and a thin square of wood that outlines the alcove in which they sit. One of the women holds her hands in her lap and looks fixedly into the distance. Her clothes are threadbare, her body thin, and in the foreground, her broken shoes and awkwardly positioned feet signify her suffering. Alongside her another woman is engaged in crochet and wears a calm, placid expression, her eyes downcast. This woman wears white clothing which contrasts with her extremely dark skin which is stretched taut over her cheekbones and over the exposed area of her chest. Peeping out from the hem of her skirt are her cracked, bare feet. There is a stillness

about these women that makes them appear to be a sculpture or a painting and their position within the wooden frame contributes to this effect. The woman who is shown crocheting a piece of clothing or cloth appears in a state of rapture, a kind of domestic bliss that, in the tradition of the domestic idyll in the history of western art, casts her as a sign of domesticated womanhood.

In this way this image borrows from a tradition of representation of women engaged in domestic tasks, caught unaware in their performance of gendered identity. I read the image as a version of the domestic idyll that affirms a very particular relation between women and work. The significance of the use of such conventions is that they work to contain, translate and neutralise that which is outside of western experience.⁸⁰

The aestheticisation of AIDS works in this manner: in order to appear in media the radical outside must be codified in a way that renders it translatable. Such codifications suggest to the viewer particular ways of interpreting images that serve to foreclose alternative ways of seeing. For instance in Image One, the use of aspects drawn from the domestic idyll convert poverty into homely virtue and elide class, gender and race oppression in contemporary manifestations of (post)colonial, global capitalism. Without a caption to reveal whether she is crocheting clothing for herself or to sell, or to explain that crochet is a form of income generation for poverty-stricken Zimbabwean women, the woman in this image and the work she performs is situated outside of the circuits of the global economy. In this way the relation between poverty, women and AIDS is rendered picturesque.

This image and the image that follows it (Image Two) portray the exterior space of the hospital. These images are followed by a series of photographs of patients inside the hospital building. The first two images work to set up a particular way of looking at the images of the interior space that follow that depends on a perception of Africa as that which is beyond the reach of western medical care.⁸¹ These images portray a poverty that because it is not explained comes to appear natural. Image Two portrays a person lying

⁸⁰ See also the first image in *A Broken Landscape* that shows the emaciated body of Joseph Gabriel in the arms of his mother, an "African Pieta".

⁸¹ I am mindful here of the fact that African medical practitioners play a crucial role in addressing the needs of people living with HIV and AIDS on the continent. I am mindful also of the fact that African scientists and doctors have been at the forefront of HIV and AIDS research. That said, what is at work in these images is an ideological separation of Africa from the west.

on a reed mat covered from head to toe with a worn blanket. The person's knees are drawn up towards their chest. At the feet of this person, part of the body of a woman is visible, a small child seated on her lap. In the foreground alongside the head of the person lying on the ground are two cooking pots standing next to the remains of a fire, smoke from which obscures the face of the person lying under the blanket. As the structure of the book until this point has presented sequential images of a single person that can be read as a narrative, I read the image that follows the image of the person lying on the reed mat as a way to decipher the first image of a patient inside the hospital.

This image (Image Three) shows the emaciated face and upper body of a man lying on a white bed. Alongside him is a woman who holds his hand in her right hand, an enamel bowl containing a small fish, whole but for a fragment torn from its middle, cradled in her left. The bowl, it seems, could be the lid of the pot that appears on the preceding page. It is possible that this man could be the figure concealed by the blanket, lying on the reed mat on the ground outside while waiting to enter the hospital. This image of the sanitised interior space of the hospital is in sharp contrast to the photograph that precedes it.

Reading these images in relation to one another casts light on the strange double page spread of the blanketed figure and the headless woman and child. The photograph of the exterior of the hospital portrays a space of non-reason, a space in which composition has gone awry, a space of "primitive" Africa where all activity takes place around the edge of a fire which does not burn but smoulders, the smoke obscuring the figure, sick, asleep or dying, beneath their blanket. The interior space of the hospital is a space of order and in spite of the absence of nurses, the hospital beds are arranged in rows, the bed linen appears clean, and the sick are being ministered to by their female family members. The civilised and civilising atmosphere of the hospital is disrupted only by the presence of sick African bodies.

The next photograph in the sequence depicting the interior of the hospital (Image Four) shows an extremely ill man being supported by a woman who is helping him to drink from an enamel mug. The woman's gaze is directed at the man she is supporting and her face can only be seen in profile. The man's head is turned towards the camera and one of his eyes is visible, the other obscured by the woman's hand and the cup. The

eye that can be seen is also an eye that looks. It appears as if the man has seen the camera and is directing his gaze towards it. The expression in his eye is one of shock or fear, that of a person who, in a moment of vulnerability has realised that they are not unobserved. The sight of this eye is an instant for me, of Roland Barthes's *punctum*. For Barthes, the *punctum* is that which disrupts what he terms the *studium*, the vast field of photographic images that one interprets by means of what one has learned to see. Of the *studium* Barthes writes:

Thousands of photographs consist of this field, and in these photographs I can, of course, take a kind of general interest, one that is even stirred sometimes, but in regard to them my emotion requires the rational intermediary of an ethical and political culture. (Barthes, 1981:26)

If the *studium* is that which I have learned to appreciate by virtue of acculturation, the *punctum* is that which resonates with my own experience, effectively creating a rupture in the *studium*. Barthes describes the *punctum* in the following way:

The second element will break or (punctuate) the *studium*. This time it is not I who seek it out (as I invest the field of the stadium with my sovereign consciousness), it is this element which rises from the scene, shoots out of it like an arrow, and pierces me. A Latin word exists to designate this wound, this prick, this mark made by a pointed instrument: the word suits me all the better in that it also refers to the notion of punctuation, and because the photographs I am speaking of are in effect punctuated, sometimes even speckled with these sensitive points: precisely, these marks, these wounds, are so many points. This second element which will disturb the *studium*, I shall therefore call *punctum*; for *punctum* is also: sting, speck, cut, little hole – and also the cast of the dice. A photograph's *punctum* is that accident which pricks me (but also bruises me, is poignant to me). (1981:26-7)

Barthes description of the way in which the *punctum* "reaches" the viewer seems to involve the transformation of the medium of the photograph itself. Certain images are not merely one dimensional but contain an element that "rises from the scene, shoots out of it like an arrow, and pierces me". The *punctum*, defined as a "cut" or "little hole", seems to tear through the structures of representation. Through this tiny opening, the viewer and the viewed are suddenly, even violently, co-present. The *punctum* as that which wounds also implies an opening of the body, an opening of the embodied viewing subject to the injury of memory, to that which is lost but which the image partially returns.

Looking at Mendel's image of the sick man being held up to drink from an enamel cup, is disturbing not only because the man has caught sight of the photographer but also because I experience his gaze as one directed at me. The fictional realm the sick man inhabits on account of the fact that for me, the viewer, he exists through, and only as, image, becomes the real. The distance that representation allows is collapsed and at once I am present at the scene of the image. The man's panicked eye catches me and seems to accuse me of that which I already know myself to be guilty; I am a voyeur of his body, of his life verging on death, of what may be his last moment. The photograph itself becomes for me an accusation.

In the same image there is another element that disturbs the *studium* of AIDS that makes up *A Broken Landscape*: on one corner of the blanket that partially covers the patient and that appears across the lower left section of the photograph is a small manufacturers' label that reads "Lady Anne" in a curling script. This tiny sign with its reference to British nobility and imperial industrialism, so incongruous in this setting where there are no other legible symbols of modernity, serves as a reminder of Zimbabwe's violent history of colonial oppression. The "Lady Anne" label and the accusing eye of the sick man articulate with one another, fracturing the vision of Africa as outside of western time and of Africans as beyond the reach of medical assistance. The appearance of these small signs is an uncommon disturbance in these images which primarily work to re-inscribe Africa as outside of modernity. For instance, each of the sick men in the three images I have discussed thus far is shown with a woman at their side who attends to their needs and offers them comfort. None of these women appear to be medical practitioners and no one of them is dressed in a nurses' uniform. While the hospital beds, with their metal frames and white sheets appear similar to those found everywhere across the world, the absence of depictions of any medical equipment or medical staff makes the space of the hospital appear to be, as discussed above, an extension of the space of the hospital compound. While these images effectively expose how hospitals in sub-Saharan Africa are under-resourced, in need of both medical supplies and equipment and nursing staff and doctors, they also cast dying Africans as beyond the reach of modern medical care.

The photographs and extended captions that accompany them in the other sections depicting hospitals included in *A Broken Landscape* also emphasize how health care systems in Southern Africa are unable to adequately address the HIV and AIDS crisis due to lack of resources and understaffing. The extended caption for the section titled “Government Hospital. Nkhotakota, Malawi” reads as follows:

Officially we have beds for 110 patients but we now have about 130 patients and 250 outpatients a day. It’s difficult to say accurately how many have died of AIDS because we have run out of reagent for testing and haven’t been able to test. We have approximately one death a day. We lack equipment, we lack staff, we don’t have medicines. We don’t even have plaster tape, so we have to use masking tape to attach drips or splints to patients’ arms. We are overwhelmed in every aspect of the epidemic. Dr Maurice Bonongwe, Director. (50)

It is apparent from this statement that Government Hospital in Malawi did, at some point, have the capacity and the equipment necessary to test patients for HIV. The reasons why the hospital has “run out of reagent” are not made clear. Without this crucial explanation Bonongwe’s words are reduced to an affirmation of what Simon Watney terms the “psychic and cultural construction” of the discourse of “African AIDS” (110). One consistent aspect of this discourse is the “singl[ing] out [of] the alleged ‘mis-reporting’ of African HIV and AIDS statistics as further evidence of ‘backwardness’ and ‘unreliability’” (110). The photographs of hospitals in *A Broken Landscape* depict crumbling outposts on the margins of bio-power yet the part played by colonisation, and its legacy in structuring relations between the hospital as institution and the institutionalised African body, is never overtly stated. That colonial history is also what permits the presence of the camera in the space of African hospitals also remains unacknowledged. Mendel’s own discomfort with the intrusive nature of his work is made apparent in his statement about the Matibi Mission Hospital sequence and as I note in my analysis below, this statement, and Mendel’s anxiety about his work along with it, are excised from the published collection of photographs. This omission of how the colonial legacy continues to determine the (post)colonial present naturalises both conditions in the hospitals and the presence of the photographer.

It is interesting to note, in relation to Image Four, the photograph in which I have identified two ruptures in the *studium* of AIDS, that for Barthes, the *punctum* is never that which the photographer intended me to see but rather that which appears in spite of the

photographer's intentions. In his essay, "Barthes's *Punctum*", art historian Michael Fried argues that most scholars who have engaged with Barthes's work on photography have overlooked this crucial aspect of how the *punctum* should be understood and defined. Fried emphasises that for Barthes, the *punctum* is not only an individual response to an image but prior to this, that which escapes or exceeds the photographer's intentions and which the photographer *has not seen*. Fried reads Barthes's work in relation to his own, particularly in relation to what he terms "antitheatrical critical thought" (Fried, 2005:545). For Fried, Barthes's assertion that the *punctum* is that which appears without the photographer's intent "is an antitheatrical claim in that it implies a fundamental distinction, which goes back to Diderot, between seeing and being shown" (2005:546).

The *punctum*, we might say, is seen by Barthes but not because it has been shown to him by the photographer, for whom it does not exist; as Barthes recognises, "it occurs [only] in the field of the photographed thing," which is to say that it is a pure artifact of the photographic event – "the photographer could not photograph the partial object at the same time as the total object" is how Barthes phrases it – or, perhaps more precisely, it is an artifact of the encounter between the product of that event and one particular spectator or beholder, in the present case, Roland Barthes (Fried, 2005:546).

Fried's analysis of the antitheatrical quality of the *punctum* complicates my reading of the disruptive capacity of the image of the man who seems to see through and out of Mendel's photograph. The inclusion of this image in *A Broken Landscape* can be read as a re-inscription of the accidental as intentional, a re-inscription that makes the image theatrical in its afterlife. My encounter with the photographed man becomes staged, a constructed encounter that occurs only in and through the field of representation within which images of AIDS circulate as commodities and their power to disturb is effectively anaesthetised.

The Commodification of Death

Through his depictions of ailing men at Matibi Mission Hospital and the women who care for them, Mendel conveys how the burden of care for people living with HIV and AIDS in Southern Africa has fallen largely on women. Importantly, his images in this

series show that African people care for one another just as people in the west do. At the same time these images depict African women performing one of the roles prescribed for them in colonial discourse, that of the mother, saintly and submissive and able to experience and withstand unlimited suffering. In “The Appeal of Experience; the Dismay of Images: Cultural Appropriations of Suffering in Our Times”, Arthur Kleinman and Joan Kleinman observe that images of people in situations of crisis are often presented without reference to the social contexts in which they are situated or to the local and global economic and political forces that determine how such crises unfold. They argue that while such images may play an important part in shaping international responses to humanitarian crises, omitting the social worlds of those depicted effectively reduces them to spectacle (Kleinman and Kleinman, 1996:7-9). While Mendel carefully portrays relationships, and in this sense recognises the humanity of those he depicts, his camera also intrudes upon private, intimate moments between people living with HIV and AIDS and those who love and care for them. It is important to remember here that in the Matibi Mission Hospital sequence, the names of those portrayed are omitted, as too are their stories. While the images themselves provide visual signs of the connectedness of those portrayed to others, and of their belonging to a wider community, they are insufficiently contextualised. The suffering of individuals becomes a sign of a generalised “African” suffering.

In the section that follows I read the remaining four images that make up the Matibi Mission Hospital sequence. These images depict the dying and death of an unnamed man. Mendel recounts how his presence at the moment of this man’s death during his first assignment documenting HIV and AIDS in Africa at the Mission Hospital in Zimbabwe was a defining moment in his career:

While I was there [at Matibi Mission Hospital] I was photographing a patient whose wife was lifting him up in his bed. As I was documenting that scene, he had a sudden seizure and died from kidney failure. On my contact sheet I can follow the sequence as he moves from life to death. These are images I have mixed feelings about: as a news photographer I have photographed many dead people, yet there is something about my role in that situation I do not feel comfortable with. Are there some moments which should be sacrosanct, exempt from the intrusion of a camera? In that situation, seconds after the man had died, and the reality of the situation began to strike me, his family began to wail and break down. I put my camera down and stopped photographing. The doctor who had been called looked at me calmly

and said, "Come on man, do your job." In that context of medical crisis it was the only constructive thing I knew how to do. (Mendel, 2001)

What Mendel terms "the reality of the situation" only strikes him after the man's death – he "sees" that what he has been photographing is not a scene but a real situation. The careful construction of "AIDS" as spectacle is radically disrupted by the "real" of AIDS. This shift from the drama and narrative of AIDS that allows for the dying to be represented as spectacle, to the "real" of corporeality, suffering, death and grief, is an instance of the ways in which AIDS confounds and exceeds representation. "Are there some moments which should be sacrosanct, exempt from the intrusion of a camera?" Mendel asks. What might be called a "crisis in witnessing" is quickly swept aside by the doctor's reply, delivered as an instruction through the homosocial rhetoric that structures relations between white men in (post)colonial contexts: "Come on man, do your job."⁸² The doctor's impatience with Mendel's quavering in the face of death is the position of one for whom the political import of telling the story of "AIDS" is greater than recognising individual suffering and grief. It is also the position of one for whom it must necessarily be so – western medical science hinges on the cleanly biological view of life and death. The doctor, confronted by pain and grief, does not lose his head and in the practice of photography, of making visible as a mode of rationality, Mendel too finds a way to hold onto the sense of things. Mendel takes up his camera again and photographs the bereaved family. "In that context of medical crisis it was the only constructive thing I knew how to do" he explains. Documenting the crisis of AIDS, identified here as Mendel's "job", is a way to apprehend death as something more than, something outside of itself. Photographing the dead is here understood to be constructive presumably because through making this one death visible, other deaths will be averted. The act of photographing the death of the unnamed man and of publishing the image transforms death itself into something of value. But what is the value of this death? Its value lies in how death is made an image of death, an image that can enter the circuits of exchange.

To take the unnamed man's death as exemplary, as a sign of the deaths of others, is to evade the significance of this one death. In this way death is made into something that I can look upon but that does not shatter me. Interestingly, Mendel's description of

⁸² I draw the term "homosocial" from Sedgwick (1985).

his discomfort about the image of the death of the unnamed man does not appear alongside the photographs in *A Broken Landscape*. Mendel's account raises the question of why and how, in the face of the radical unmaking that is AIDS, one does anything other than, like the family members of the man who died, "wail and break down". Omitting the account, and therefore also the question of how to respond when one is witness to another's death (which one is even when looking at an image rather than being present at the time of the death) seems a deliberate attempt at diminishing the disturbing appearance of this image. The absence of caption also makes it possible to interpret the image not as the instant of the man's death but as seizure, coma or trance.⁸³

The sequence of images depicting the death of the unnamed man begins with a photograph of a woman shown at his bedside (Image Five, *Figure 2*). Their relationship is shown to be an intimate one, their togetherness emphasised by another man, visible in the background of the image and who is depicted lying alone on a bed, his hands covering his face. The woman at the bedside is entirely absorbed in the man's suffering, her eyes are directed at him and her face is close to his. The man appears extremely still – odd that one perceives this in a still photograph – almost like a corpse. His eyes are directed at the ceiling but he does not seem to see. The woman's hands are moving above his face, perhaps she is about to adjust his blankets, or, as the next image indicates, lift him from the bed.

In the photograph that follows (Image Six, *Figure 3*) the woman is using all her strength to support the sick man's body. She is looking at his face and seems terrified, resolute or desperate. The man is in pain, his position is awkward, with his lips apart he looks into the distance and seems about to cry. An open door and an empty bed just beyond it are visible on the far left of the image, behind the woman. The pillow upon which the man was lying seems to hold his shadow, the stain of his body. The pillow seems to be torn, worn through, the folds of the fabric like skin, something visceral, repulsive, opening; a metaphor for the body that has lifted away from the bed.

⁸³ I am grateful to Louise Green for reminding me of the world outside of AIDS and for suggesting to me that it is the content of the book as a whole that leads the viewer to read the death in this image as death rather than seizure, coma or trance. In my reading of the image I argue that the image itself contains visual markers that indicate that the man has just died. That said, it is useful to think through how seeing through the lens of AIDS produces a certain kind of interpretation, one over-determined by the presence of death. The importance of remembering that this may not always be so is crucial.

The image that follows is the image of the instant of his death (Image Seven, *Figure 4*), the sheet around his body now a shroud. His eyes rolled back, half open, in the horrifying pose of death, his body slumped against the woman. On the right hand side of the photograph, only partially visible is the doctor, a bearded white man equipped with the accessories of modernity; spectacles, a watch on his arm that is extended, reaching to the chest of the dead man, and in his hand the stethoscope, the instrument that enables him to pronounce the man as dead.

The final photograph in the Matibi Mission Hospital sequence shows three grief-stricken women outside of the hospital building (Image Eight, *Figure 5*) in the compound that was visible in the first two images in the series. In this image I see that the world of the mourners has been shattered but the composition of the image is such that their grief does not shatter me. The photograph shows the mourners from behind, their arms around one another forming a tight circle, their faces hidden from view. I am closed out, positioned safely outside of the intensity of their grief. I see their sorrow but I do not experience it. Their world is one of disorder, one in which reed mats are scattered haphazardly on the barren ground, empty bowls are upturned and a blanket has been slung between the branches of a tree that casts no shade. This inhospitable, “broken” landscape bears no resemblance to my own, nor, I imagine, to that of many of the readers of *A Broken Landscape*.

What I see in this image that seems to reflect me is the uncanny similarity between two dark spaces in the concrete wall in the background of the photograph to a pair of hollow, expressionless eyes.⁸⁴ The notion that these dark spaces in the centre of the concrete wall are a pair of eyes transforms all the dark spaces on the concrete structure into eye sockets, all of them looking down at the three grieving women in their desperate embrace. These “eyes” do not so much return my gaze as absorb it, a metaphoric mirror of the eyes of the mourners that do not see me looking at them.

⁸⁴ Those familiar with architecture in Southern Africa will recognise the gaps in the concrete structure as air-bricks, placed to allow air to circulate through buildings. Their appearance high up on the bare wall, which would allow a small amount of light into the building without enabling those inside to see out, gives the structure (most likely an ablution block) the appearance of a prison. As there is no caption to explain the building’s function, its appearance only contributes to the desolate effect of the image.

Who owns this death?

The composition of Mendel's photograph of the three grieving Zimbabwean women articulates his anxiety about his own presence even as the omission of his account explaining the image erases that uncertainty. If the image of the instant of the unnamed man's death represents the "real" interrupting the constructed narrative of AIDS, the image of the mourners marks the separation between those who look and those who are looked at and restores the order of representation; an order within which representation is infinite and does not halt for the dying any more than it averts its eyes at the sight of the dead. While it is not possible to know whether the women depicted in this image were aware of the presence of the photographer, and if they were not, how they might have reacted had they seen him, it is instructive to read Mendel's image in relation to an image of a grief-stricken woman photographed by Don McCullin on his last major war assignment in Beirut in 1982. Aida Edemariam, a journalist who interviewed McCullin for *The Observer* in 2005, describes this photograph and the incident that led to its production:

One of the most striking [photographs] is of a woman in mid-flight around a bombed building, propelled by grief; she saw McCullin raise his camera and attacked him, punching and slapping. It turned out her entire family had just perished. Hours later she was killed by a car-bomb. (Edemariam, 2005)

The woman's furious response to the presence of the photographer raises the question of what the practice of documenting social suffering means for those who are represented. Like the three women in Mendel's photograph, the woman in McCullin's photograph of war-time Beirut is not named. The nature of her death is recounted without an explanation of how this information was obtained. Her fury at being made something other than herself, a sign of the tragedy of war, is packaged for consumption. The photograph in which she is depicted refusing to be photographed circulates within the global image economy, an object that, like Mendel's images of the death of the unnamed man and those who mourn him, can be bought and sold.

Throughout *A Broken Landscape* the appearance of awareness on the part of those being photographed and their tacit or overt acceptance of the presence of the

photographer grant legitimacy to the collection. The importance of obtaining consent from those depicted is underscored by Mendel's acknowledgements, which appear on the last page of his book. After a section acknowledging the role played by friends, doctors (who presumably provided access to hospitals), non-governmental organisations and publications in which some of the images first appeared, is the following statement:

Behind every picture there are individuals, families, carers, organisations and institutions, too numerous to mention, whose practical help and kindness will not be forgotten. Finally I must pay tribute to the people I photographed, most of them living with HIV or AIDS, who welcomed me into their lives with such generosity and were brave enough to allow themselves to be photographed, believing these images could make a difference. (Mendel, 2001)

Mendel recognises here that for many people living with HIV and AIDS there is a great deal at stake in being photographed. At the same time there is a curious conflation between Mendel's project (photographing people living with HIV and AIDS in the belief that such images could make a difference) and the subjects of his photographs (who, it is implied "allow themselves to be photographed" because they too believe such images could make a difference). The passive construction "allow themselves to be photographed" neatly sidesteps whether Mendel's subjects explicitly gave him permission to photograph them or not. That all Mendel's subjects "welcomed him into their lives with such generosity" is not borne out by all the images in *A Broken Landscape* and the image of the three grief-stricken Zimbabwean women in particular, disrupts what could be termed the construction of consent in the text.

As I noted above in my discussion of how Mendel's text is structured, *A Broken Landscape* contains several photographic essays – "portraits" – of individuals living with HIV and AIDS. Each of these portraits is accompanied by personal testimonies. In the section that follows I argue that the inclusion of testimony is one of the primary ways in which consent is implied in the text. I consider how these narrative accounts serve as a kind of guarantee, both of Mendel's ethical position in relation to those he represents and of the authenticity of his subjects. In my reading of Mendel's photographs of Mzokhona Malevu, a young man who lived in Enseleni Township in KwaZulu Natal in South Africa, I analyse how AIDS is constructed as a visual story and how testimony as a "truth discourse" naturalises that construction.

AIDS as Visual Story: Mzokhona Malevu. Enseleni Township, South Africa

A Broken Landscape contains several “portraits”; image sequences that depict an individual living with HIV and AIDS and those who care for them. These portraits provide a more detailed insight into the lives of their subjects than a single image would allow. There are nineteen pages depicting the life and death of Mzokhona Malevu who was twenty-nine years old when he died in September 2000.⁸⁵ This series of images, the longest devoted to an individual in the collection, forms an intimate account of his illness and death and of the people who loved and cared for him. Of this sequence Mendel states:

I’m proudest of a story I did this past year on one person, Mzokonah Malevu, a person with AIDS in South Africa. I think I achieved real depth. I began to photograph him in April of 2000. And I went back to visit him and his family on four different occasions over the year, leading up to attending his funeral in December. I made a strong, personal connection with him and his family, who were taking care of him with amazing love within the context of extreme poverty. Mzokonah was living in a three-room squattershack with 21 people. He was open and out about his disease. He had decided that he wanted his funeral to be an AIDS-education event and he made me promise that when he died I would come and take photographs at his funeral. He wanted to tell his story to the world and I was a sort of conduit for him to do it. The quotes which I collected from him, together with the images which tell his story from life to death, make a powerful, personalized statement. (Mendel, 2001)

Mendel’s description of his relationship with Malevu and with his family, and the photographs he took of him “which tell his story from life to death” present a marked contrast to the images that chronicle the death of the unnamed man at Matibi Mission Hospital.

The first image in the series depicting Mzkhona Malevu is a formal head and shoulders portrait, one in which the sitter is well aware of being photographed and is posed for the camera (Image Nine, *Figure 6*). Malevu’s face and clothing are shown in sharp focus while the background of the image is blurred. His eyes are at the very centre of the image and draw the viewer’s attention; he appears to be looking out of the photograph, his gaze both haunting and haunted.

⁸⁵ In *A Broken Landscape* the date of Malevu’s death is recorded as 29 September 2000. In Mendel’s statement cited above he states that he attended Malevu’s funeral in December 2000.

Like Alexander Gardner's 1865 portrait of Lewis Payne, a young man who was photographed in prison while awaiting execution for his role in the assassination of President Lincoln, Mendel's portrait of Malevu portends his imminent death. In *Camera Lucida* Barthes reads Gardner's portrait of Payne in the following way: "The photograph is handsome, as is the boy: that is the *studium*. But the *punctum* is: *he is going to die*" (Barthes, 1981:96). In Mendel's portrait, Malevu wears the look of a condemned man. The poignancy of the image lies in its reappearance in the book a few pages later, in an image that shows Malevu's funeral (Image Ten, *Figure 9*) which appears after several photographs that show Malevu's daily struggles living with AIDS in conditions of extreme economic poverty, of his corpse being prepared for burial, and of his funeral procession. The photograph of the funeral shows the church choir with Malevu's coffin in the foreground. Positioned on top of the coffin is an enlarged, framed reproduction of the portrait that began the sequence of images. The appearance of this photograph within the photograph of Malevu's funeral is a haunting signifier of how, for those living with AIDS without access to treatment, ill health deteriorates rapidly into death. Time has been compressed for Malevu and his passage from life to death radically accelerated.

Malevu's life-span has been truncated by his death from AIDS but it is also the mode of representation of his experience, one structured by the desire for narrative coherence, which abbreviates his life in this way. The reduction of Malevu's entire life story to a few frames is also that which makes possible the appearance of his story. An argument can be made that if Malevu's life is to be recognised within the public sphere it must be represented and in order to be represented it must be made representable. Yet the impossibility of capturing the complexity of a person's life is only part of what is at work here. Judith Butler's argument about the need "to parse the various ways that representation works in relation to humanization and dehumanization" (145), is prescient here. In *Precarious Life*, Butler thinks through this relation by way of the philosophy of Emmanuel Levinas, particularly in relation to his writings on the concept of the "face". For Levinas, the face is the site of the recognition of the vulnerability of the human and it is through the face that I recognise my relation to the other. It is important to note here that for Levinas the face is not the physical face of a person or even a human face but rather signs of precariousness, "the extreme precariousness of the other" (Levinas,

1996:167). Through her reading of Levinas's work Butler articulates how violence can be enacted through the production of the face within and through representation. She refers to the appearance in the media in the United States of images of Yasser Arafat, Saddam Hussein and Osama Bin Laden in the context of the "war against terror" and draws attention to how representation can "effect a dehumanization" (Butler, 2004:141).

When we consider the ordinary ways that we think about humanization and dehumanization, we find the assumption that those who gain representation, especially self-representation, have a better chance of being humanized, and those who have no chance to represent themselves run a greater risk of being treated as less than human, regarded as less than human, or indeed, not regarded at all. We have a paradox before us because Levinas has made clear that the face is not exclusively a human face, and yet it is a condition for humanization. On the other hand, there is the use of the face, within the media, in order to effect a dehumanization. It would seem that personification does not always humanize. For Levinas, it may well evacuate the face that does humanize; and I hope to show, personification sometimes performs its own dehumanization. How do we come to know the inhuman but humanizing face, for Levinas, and the dehumanization that can also take place through the face? (Butler, 2004:141)

It is this paradoxical relation between representation and dehumanization, I have argued, that attends the appearance of the bodies of those living with HIV and AIDS. The negation of the subjectivity of the person with HIV and AIDS is effected precisely in and through their entry into the symbolic order, here identified as the realm of representation. Caught between life and death, but always already given over to death, these are subjects for whom subjectivisation is simultaneously desubjectivisation. The terms of their inclusion within the symbolic are paradoxically those of radical exclusion; as those against and through whom "the human" is constituted, non-subjects appear only in order to disappear. Their (dis)appearance through the narrative of AIDS in Africa marks the formation of the constitutive outside and augments the being of the true and proper *living* subjects of western modernity. The narrative of people living with HIV and AIDS in Africa is one that follows a sequential, predictable logic and that always ends in death. The construction of a coherent narrative of "AIDS in Africa", one that follows a sequential logic that is always resolved in death, restores a mode of rationality in the face of the radical unmaking of HIV and AIDS.

Anxiety about the limitations and purpose of representation emerges through Mendel's statement about how his practice has shifted in response to his sense that "the story of AIDS" exceeds the photographic medium:

I've also come to feel that images aren't enough to express the story of AIDS. What I've found very effective is combining visuals with personal quotes from the people I'm photographing to give them a voice alongside their image. I've used this approach in exhibitions, on the website (www.networkphotographers.com/aidsinafrica) and in a book I'm publishing this fall called *A Broken Landscape: HIV and AIDS in Africa* (supported by Action Aid, a charity involved in many AIDS- and poverty-alleviation projects in Africa). It has also become a priority for me that my work be used and seen in the countries where the photographs have been taken. I am currently working with Action Aid to produce a series of 20 educational posters using my images and the quotes I have collected from my subjects. These will hopefully be widely distributed in Africa. (Mendel, 2001)

Without the addition of testimony, Mendel implies, the voices of the subjects of his images cannot be heard. Once "personal quotes" have been attached though, Mendel's mute Africans are given "a voice alongside their image". The "voice" of the photographed subject is attached to the image in response to photography's contested claim to representing the truth or the real. This "voice" of truth comes to substitute for visual truth. At the same time testimony affirms the truth of the visual. If we consider the way in which Malevu's testimony operates in the sequence depicting his life and death, it becomes apparent that its function is as a discourse of verification, one that affirms the vision of the photographer. The extended captions that accompany the photographs in this sequence consist of two pages of Malevu's testimony and a one page account of his death related by Nancy Khuswayo, AIDS counselor. Mendel's photographs mirror the script of Malevu's testimony. For instance, the last section of Malevu's testimony reads as follows:

I was given some drugs, which made me feel much better, but I cannot afford them now. I have heard that in overseas countries the government provides drugs and food free for people with AIDS, but here in South Africa there is nothing now. At the clinic they often say there is nothing they can do. You must go home. It is not fair. People overseas can get better from the good drugs they are given, while we in South Africa have to die. (Mendel, 2001:74)

The sequence of images depicting Malevu's life and illness reinforces the notion that his premature death is inevitable. The first image (Image Nine, discussed above) establishes

Malevu as a man condemned, a young man but one who has glimpsed his own death, a tragic image, perhaps only made tragic by what is, inevitably, to come. Two images follow in which Malevu is shown engaged in the everyday life of the well; one an image of Malevu absorbed in a card game surrounded by smiling family members, the other a photograph in which Malevu himself is smiling, his ecstatic face appearing through the space between the arm and the body of a person in the foreground, their body large, dark and out of focus (Images 11 and 12). These images accentuate the suffering and sorrow that saturate the remaining images in the sequence. Image 13 is a double-page spread depicting Malevu's sleeping quarters. The photograph shows Malevu in his bed on the far right-hand side of the image; he is awake but appears in a dreamlike state, seemingly unaware of the presence of the photographer. Alongside him on the floor are the seven children with whom he shares his room, sleeping or feigning sleep, one child returning the camera's gaze. The second page of Malevu's testimony appears overleaf:

My father is employed sometimes doing piecework on construction sites and my mother works as a maid for whites in Richard's Bay. We live in two rooms here. There is my mother, my father, their eight children and 11 grandchildren – 21 of us altogether. I sleep on the bed here in this room, with seven children sleeping on the floor next to me. Sometimes we do not have enough food to go round. My father usually bathes me early in the morning before he goes to work, but since recently we have to pay for water which he collects at the communal taps. It is 60 cents for a bucket. Now even some water for washing can be a problem. (Mendel, 2001:74)

The photograph that follows Malevu's testimony (Image 14) is an image of Malevu's father washing his son's head. Images 15 and 16 portray Malevu's deteriorating condition (see *Figure 7*), his hospitalisation (Image 17), and the care provided him at home by his brother and sister (Images 18 and 19).

These images are followed by Nancy Khuswayo's testimony which provides an account of Malevu's death. The photograph on the facing page (Image 20) shows the arms and part of the legs of a man, presumably a coroner or undertaker, crouched behind Malevu's head and laying a sheet over his corpse. Only Malevu's face is visible through a hole in the heavily embroidered cloth. Malevu's lips are slightly parted and stretched over his teeth, their pearlescence and the tiny sliver of whiteness visible just beneath his closed eyelid, the only disruptions to the otherwise extreme contrast between his dark head and the white death-sheet and the white-gloved hands of the coroner which are shown beside

his face. Images 21-26 depict the funeral procession, Malevu's coffin being carried to the church, a grieving family member, the choir at the funeral with the coffin and portrait of Malevu in the foreground, a keening woman bent double with grief during the funeral service and, finally, Malevu's father standing in his son's grave (See *Figures 8, 9 and 10*).

Read collectively without the accompanying testimony, the images of his life, death and funeral create a coherent visual narrative. What then is the purpose of Malevu's narrative account? If "images aren't enough to express the story of AIDS" and testimony is included to address this failing, why do Malevu's words not say more? While his account provides additional contextual information (that the provision of water has been privatised, the occupations of his parents), the voice he is given does not provide a more complex picture of his life nor does it contest the photographer's vision. Instead it works to affirm the visual story of AIDS Mendel presents. In the inclusion of testimony lies a claim to authenticity, a claim that works by creating the illusion that the vision of the photographer and that of his subject are one and the same, even when that subject has passed from life to death:

He [Malevu] had decided that he wanted his funeral to be an AIDS-education event and he made me promise that when he died I would come and take photographs at his funeral. He wanted to tell his story to the world and I was a sort of conduit for him to do it. The quotes which I collected from him, together with the images which tell his story from life to death, make a powerful, personalized statement. (Mendel, 2001)

Mendel's assertion is that the story of Malevu's life and death that he tells is, in fact, the fulfillment of Malevu's desire "to tell his story to the world". This claim is an interesting one for a number of reasons, not least of which for the way it disavows the constructed nature of the visual story of Malevu's life. It also points to how the increasingly important place given to narrative in representations of human subjects, particularly non-western subjects, works to secure photography's contested claim to documenting the real. Mendel's description of himself as the "conduit" that made it possible for Malevu to tell his own story to the world implies that the story of AIDS that is told here is a transparent one, a true story told in the authentic voice of the "native" subject. The inclusion of testimony in representations of people living with HIV and AIDS serves to conceal the

fact that, as McCullin observes, “AIDS will go away from our imaginations if editors and photographers and creative people don’t constantly make it *appear*”. The inclusion of the “native voice” through testimony in representations of people living with HIV and AIDS is a strategy in the production of the “truth” of AIDS and not, as the popular media would have us believe, “the true story”.

The inclusion of testimony in Mendel’s work is also connected to the fact that in order for representations of people living with HIV and AIDS to have political currency in South Africa, recognising the agency of those depicted, and more importantly, providing an indication that such agency has been recognised, has become a necessity. This has come about because of the intense debate around access to anti-retroviral therapy and the emergence of the highly visible and articulate activist movement campaigning for the rights of people living with HIV and AIDS in South Africa, the Treatment Action Campaign (TAC). One of the last images in *A Broken Landscape* shows a group of South African AIDS activists holding hands and toyi-toying at a march at the International AIDS Conference held in Durban in 2000 (see *Figure 11*). Alongside the image is a statement by Zackie Achmat, the chairperson of the TAC:

The importance of this march historically is that it helped to change international perceptions. The image of AIDS in Africa is usually one of powerless people, emaciated and dying. What the march showed is that there are many of us who are healthy and fighting to stay healthy. (194)

Mendel’s photograph of the march captures the energy and vitality of the activists, all of whom are wearing t-shirts issued by the TAC that read “HIV-positive”, and who are shown actively campaigning for their rights as citizens to be recognised. This photograph presents a different perspective on HIV and AIDS in Africa from most of the other images in the book and powerfully conveys how the TAC has created the space for the emergence of new and “positive” HIV-positive identities.⁸⁶ Like ACT UP in the United States in the 1990s, the TAC has played a crucial role in asserting the presence of people living with HIV and AIDS in a context of silence and shame.

In 2001 *A Broken Landscape* was exhibited at the National Gallery in Cape Town as part of the “Positive Lives” exhibition. During the course of the show, Mendel began work on a new series of images that reflected the changes that were occurring in South

Africa as AIDS activists began to challenge the state and to reconfigure how people living with HIV and AIDS were perceived. These images move away from what art historian Svea Josephy, referring to *A Broken Landscape*, describes as a mode of “social documentary in its most conventionalised and traditional form” (2005:8). In his new work, a series of portraits of people living with HIV and AIDS who have access to anti-retroviral therapy through the *Médecins Sans Frontières* clinic in Khayelitsha, an informal settlement outside of the city of Cape Town, and through clinical trials in Cape Town itself, Mendel makes use of colour, draws attention to the fact that the photographs are constructed, and emphasises personal testimony.⁸⁷

In her essay “Departures”, Svea Josephy traces how the practice of documentary photography in South Africa has changed since the end of apartheid. She observes that the “rigid divide between ‘documentary’ and ‘art’ has eroded considerably and that “Mendel has grown from a ‘typical concerned journalist’ to a point at which he can describe himself in an interview as an ‘activist conceptual artist’” (Josephy, 2005:10). Mendel’s new images are intended to highlight the work of *Médecins Sans Frontières* and of the TAC and in his words, “both challenge the images on the walls [the photographs that constitute “A Broken Landscape”] and explore new ways of depicting people living with HIV and AIDS” (Mendel, 2002:24). In this statement Mendel acknowledges the need to challenge his own practice, and indeed, the contrast between these new photographs and his earlier work is striking (see *Figure 12*).⁸⁸

Of particular importance is the way in which the images were composed: Mendel created large frames using gaffer tape and invited his subjects to position themselves within the frames in the way in which they wished to be seen. Many people chose to look directly at the camera, rejecting the conventions of traditional documentary photography

⁸⁷ See Mendel (2002). The people Mendel portrayed in this new series were among the first in the country to access treatment outside of the private health sector. At this time high-ranking government officials were contesting both the efficacy and safety of anti-retroviral drugs. Universal access to treatment for South Africans living with HIV and AIDS seemed very remote. In 2002 there were an estimated 400 000 people living in Khayelitsha of which approximately 40 000 people were living with HIV and AIDS. MSF began their work in Khayelitsha in 1999 and set up three HIV and AIDS clinics in 2000. By the middle of 2002 MSF were treating 177 people with anti-retroviral drugs. See Goemaere (2002).

⁸⁸ Figure 12 is a portrait of Nompumelelo Payi, an HIV-positive woman who lived in Khayelitsha and who Mendel photographed at the National Gallery in Cape Town in 2001 where she was a participant in the Memory Box project at the Positive Lives Exhibition. I conducted several interviews with her in 2001 and 2002, excerpts of which appear in Morgan et.al, 2001. Nompumelelo died in 2003.

and effectively returning the gaze of both the photographer and viewer. Josephy observes that these images can be situated “somewhere between the realm of portraits and documentary (or perhaps ‘self-portraits’ in the sense that they reference an African tradition of studio photography where the sitter plays a crucial role in the construction of his/her identity)” (2005:8). In her reading of Mendel’s portraits as “perhaps ‘self-portraits’”, Josephy overlooks how the admission of agency itself is staged. Taken in by the persuasive trick of testimony as truth, Josephy argues that in Mendel’s images the photographer has all but disappeared and it is the subjects themselves who have taken their own portraits.⁸⁹ In the context of the TAC’s demand that the rights of people living with HIV and AIDS be recognised, Mendel’s reinvention of himself as “activist conceptual artist” and the shift in his practice makes strategic sense. The trend towards the narrativisation of the visual in his work is the most cogent sign of his response to this demand.

The notion that it is not the photographer who directs the way the image is produced, nor provides the caption, but the person photographed who tells their story and thereby instructs the viewer as to how to read the image, releases the photographer from the burden of failing to represent the “truth” of the other. The photographed subject relates their story, provides an account that, once attached to the image, allows the image to be read as continuous with their testimony. In the concluding section of this chapter I interrogate how testimony has been used to produce “authentic” subjects through whom the “truth of AIDS” can be revealed.

Against the Authenticity of Testimony

In recent times a great deal of critical attention has been focussed on “testimony”. This interest in testimony has engaged the attention of theorists across a range of disciplines including literature, political science, anthropology and psychology. While these disciplines have always engaged with testimony to some extent, the renewal of interest in first-person narrative accounts is connected to studies of the *Shoah* or Holocaust and

⁸⁹ See also Tim Trengrove Jones’ critique of Mendel’s *A Broken Landscape* (2002) and Michael Godby’s defence of Mendel’s work (2006).

more recently, in relation to national reconciliation commissions.⁹⁰ In particular, testimony has come to be the vehicle for the voice of the oppressed, a genre that opens a public discursive space to those previously marginalised within, or radically excluded from, discourse.

The increasing narrativisation of the visual in Mendel's work can be read as part of this broader turn to testimony, particularly because so much of his work centres on South Africa where testimony has been accorded a political valence. In her examination of the shifts in the practice of South African documentary photographers in the wake of the transition to democracy, Josephy notes that the inclusion of testimony in Mendel's work can be connected to a more general foregrounding of narrative in cultural practice in South Africa after the Truth and Reconciliation Commission:

In documentary photography of the apartheid era, the only text provided was generally the photographer's captions. Now, in the work of Mendel, the photographer is a witness (in the post-TRC sense), who passes on oral testimony as well. This testimony takes the form of extended captions, in which the subjects tell their own stories – in the first person, in their own words. In this narrative technique, the documentary photographer is the recorder of the story and of the image of the sitter, rather than the interpreter of the sitter and situation. This is a collaboration, a combination of the story the photographer wishes to tell and the one the sitters are trying to tell, and, as such, represents a modest departure from traditional documentary narrative in South Africa. (Josephy, 2005:9)

Josephy's argument, that the inclusion of testimony in Mendel's work means that he is not merely a photographer but a "witness", and that his work is one of collaboration between photographer and subject, is precisely that which I have argued here is the ruse of testimony as guarantor of the authenticity of the photographed subject. To bear witness is to be bound up in the story that is recounted, to be inseparable from that which is recounted. To bear witness also often implies a primary relation to the event; to be physically present as the event occurs and it is this being present that enables the production of a "true" account.

⁹⁰ On testimony and the *Shoah* see Shoshana Felman and Dori Laub (1992). For a different and more critical approach, see Agamben (1999). The central role of testimony in the work of truth commissions is evident in the official reports from Argentina, Chile and South Africa. See *Nunca Mas: The Report of the Argentine National Commission on the Disappeared* (1986), *Report of the Chilean National Commission on Truth and Reconciliation* (1993) and *Truth and Reconciliation Commission of South Africa: Report*, 5 Volumes (1998). On the South African Truth and Reconciliation Commission see Posel and Simpson (2002); Kistner (2003), Ross (2003) and Young (2004). See also Antjie Krog's *Country of My Skull* (2002) and Erik Duxtader's insightful work on the concept of reconciliation.

It is interesting that for Josephy, Mendel becomes “witness” when engaged in the production of what can be understood as the most deliberately constructed series of photographs in his oeuvre. Documentary photography, the image-making genre once understood as an accurate record of the real, has been dismissed as inadequate to the task of telling the whole story. It is precisely because Mendel’s new images break with the documentary conventions that they are read as revealing the truth of their subjects. This points to how testimony has been revived as a marker of truth. In his most recent work, “The Harsh Divide”, an interactive, animated series of digital images produced for the BBC and available for viewing on the internet, Mendel takes photography to the limits of its form.⁹¹ These images, which appear much like a stilted film, are accompanied by the recorded testimonies of those they represent, their “real” voices testifying to their authenticity and providing signs of their humanness, which would, otherwise, not be apparent.

In this chapter it has been my aim to show that testimony itself is a form of representation and that it cannot simply be attached to dehumanizing visual representations as a counter-measure. I have also shown how testimony has been used to both situate and reveal the “truth” of AIDS in and through the bodies of black Africans. What is effected through this production of the authenticity of the “native” subject is something more than the “true” story of AIDS. If subjectivity in the west is radically decentred, characterized by uncertainty, and inherently complex, the testimony of “native” subjects testifies to the persistence of transparent subjectivity. If to be human is to have interior depths, to harbour secrets so complex they can only ever be partially revealed, and then only to a chosen few, then the exposed lives of Africans living with HIV and AIDS, untainted by the arts of deception that mark the modern subjects of the west, are not really human at all. Instead these are humans reduced to the inhuman in order to remind the proper humans of what it means to be human.

As my readings of Mendel’s work shows, the field of possibility for the representation of people living with HIV and AIDS in Africa is severely constrained both by the history of dehumanising codes of connotation and by the relation between

⁹¹ See www.channel4.com/health/microsites/0-9/4health/sex/shi-divide.html

“Africa” and the global market. The production and circulation of the photographs I have discussed in this chapter expose how, for people living in the borderlands of the bio-political, life must be purchased and death can be sold. The question of who profits by the production of such images is one I take up in the following chapter where I consider a series of portraits made by South African HIV-positive women of their own bodies.

University of Cape Town



Figure 1



Figure 2



Figure 3



Figure 4



Figure 5



Figure 6



Figure 7



Figure 8



Figure 10



Figure 9



Figure 11

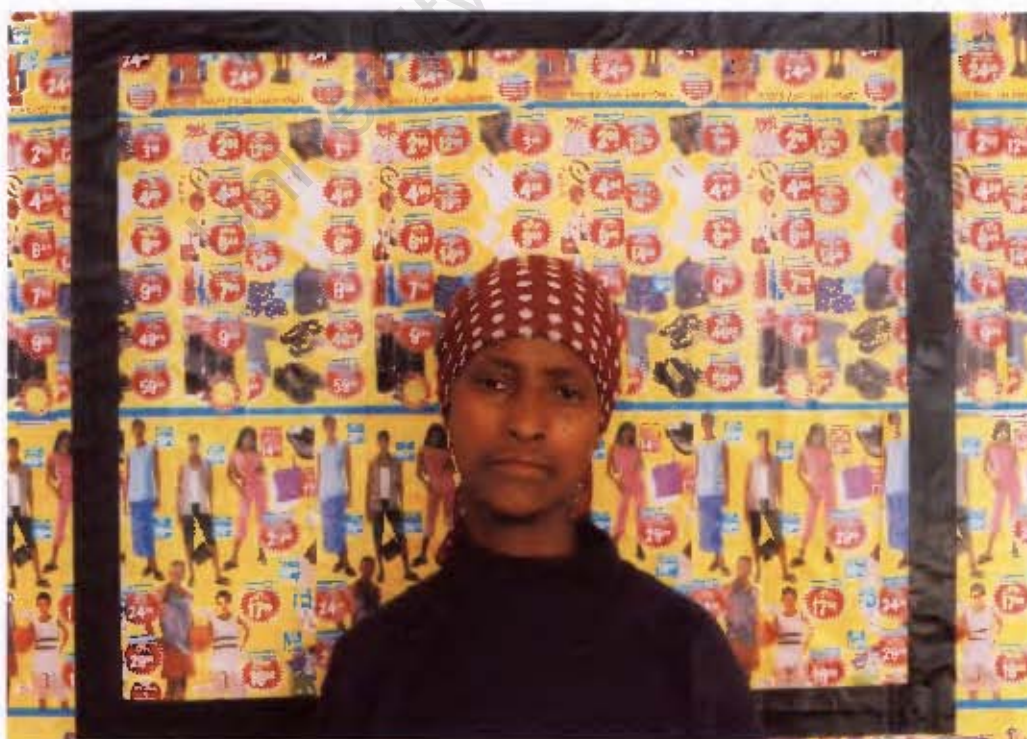


Figure 12

Chapter Five

Bodies of Truth: Authenticity and Exposure

The obligation to confess is now relayed through so many different points, is so deeply ingrained in us, that we no longer perceive it as the effect of a power that constrains us; on the contrary, it seems to us that truth, lodged in our most secret nature, “demands” only to surface; that if it fails to do so, this is because a constraint holds it in place, the violence of a power weighs it down, and it can finally be articulated only at the price of a kind of liberation. Confession frees, but power reduces one to silence; truth does not belong to the order of power, but shares an affinity with freedom: traditional themes in philosophy, which a “political history of truth” would have to overturn by showing that truth is not by nature free – nor error servile – but that its production is thoroughly imbued with relations of power. The confession is an example of this. One has to be completely taken in by this internal ruse of confession in order to attribute a fundamental role to censorship, to taboos regarding speaking and thinking; one has to have an inverted image of power in order to believe that all these voices which have spoken so long in our civilization – repeating the formidable injunction to tell what one is and what one does, what one recollects and what one has forgotten, what one is thinking and what one thinks he is not thinking – are speaking to us of freedom.

Michel Foucault⁹²

By surveying these scars from my head down to my feet, I have sketched a possible autobiography, summarized in an archaeology of the skin. The only thing that matters in one's personal story is whatever has been ciphered on the body and thus continues to talk, to narrate, to simulate the incident responsible for its inscription.

Severo Sarduy⁹³

In this chapter I discuss a series of self-portraits by HIV-positive women. Unlike the photographs I read in the previous chapters, these are not images produced by professional visual artists or photojournalists. I say this not to diminish the aesthetic value of these portraits but to make clear that these images cannot be interpreted in the same

⁹² Foucault (1976:60).

⁹³ Sarduy (1995:vii)

way as the photographic images I discussed in chapters three and four, nor can they be interpreted as self-portraits in the traditional sense. These images were created through a workshop process intended to be both therapeutic and to produce material for a book to draw attention to the plight of people living with HIV and AIDS in South Africa. Although they have entered the public domain as artworks, the conditions of their production means that they cannot be read through the codes of connotation by which self-portraits are ordinarily interpreted. Instead, I describe the images, and the women's explanations of the stories the works contain. My concern in this chapter is both to offer an alternative to the hegemonic modes of representing HIV and AIDS in Africa and to allow space for a different kind of narrative. Also and perhaps more centrally, this chapter explores the implications of circulating images as the authentic expressions of experience which make visible the transparent "truth" of AIDS as it is written on the body.

I begin this chapter with two epigraphs that concern the formation of the subject through testimony and that offer two quite different views of how the "truth" of the self, a truth that is thought to be lodged in the body, emerges, and what that emergence signifies. The first is drawn from Michel Foucault's account of how the secularisation of the ritual of confession has been a key aspect in the expansion and intensification of power's hold over life. Extracting the hidden truths of the subject from the depths of the body has provided the means for what he terms "the entry of life into history", the formation of bio-power. Besides the disciplines engaged in wresting truths from our bodies – medicine, law and science – , a vast network of confessionals, public and private – television talk shows, psychoanalysis, truth commissions, autobiographies – the confiding of our inner-most thoughts to strangers, and to those we are most intimate with, constitute our social existence. For Foucault the confessional in all these varying forms is instrumental in exerting control not only over individuals but over the population as a whole.

The second epigraph, taken from Cuban writer Severo Sarduy's autobiographical meditation on embodiment, articulates a self-confessing body, a body that "simulates the incident responsible for its inscription" but also one that narrates beyond that incident, the body conceived as a story that tells itself. Sarduy's writings, within which his own body

both records and transmits his experience of the world, indicates how story-telling might be conceived as a site of agency. For him the infinite story-telling capacity of the body can be thought as a site of resistance to the repressive regularisation of disciplinary power.

Indeed, the confessional not only permits power to access the body but also constitutes a claim to subjectivity. The provision of testimony provides the point of entry to the sphere of the law and to recognition as a juridical subject. While the religious confessional restores the speaking subject to a state of grace, testifying to traumatic experience has often been understood as restoring (at least to some degree), the coherence of the subject. Testimony thus depends on a particular conception of the subject, a subject who can speak, a subject who can (and will) speak the truth, a subject who in his or her originary state was coherent, a state to which they can be restored. Telling one's personal story has, in South Africa in the wake of the Truth and Reconciliation Commission, come to be understood not only as a vital aspect of personal healing from trauma but as a social good.⁹⁴ Testimony has come to be the vehicle for the voice of the oppressed, a genre that opens a public discursive space to those previously marginalised within, or radically excluded from, discourse. In this sense testimony serves as a means of access to a particular kind of visibility, and even agency, within particular fields.

Yet to testify is also to occupy a position of vulnerability and of exposure. In this chapter I consider how testimonial articulations, confessional self-representations, provide a point of access to what is thought to be the authenticity of the subject. I am interested in what the bounds of the testimonial field are and what it means to exceed these bounds. I understand testimony to be a place offered by those who hold power to those who do not and as I show here through my analysis of a series of self-portraits made by HIV-positive South African women of their own bodies, staking a claim on a place within the social, political and juridical realms through testimony and through representations of the body is riddled with complexity. This is particularly so for HIV-positive, economically and socially marginalised black women for whom the body has long been a site of subjugation and whose experiences have long been silenced. In this

⁹⁴ See for instance Deborah Posel's recent article on South Africa as a confessing society (Posel, 2006:8-9).

moment in which testimony is celebrated as a sign of liberation, we would do well to remember Foucault's rejoinder that the production of truth "is thoroughly imbued with relations of power" and the notion that there is a fundamental relation between confession and freedom is "to have an inverted image of power".

The vexed question of how it can be possible for subjugated people to represent themselves through the very discourses of power within which they are unmade as subjects has been most famously addressed by Gayatri Spivak in her foundational essay, "Can the Subaltern Speak?" Spivak begins by interrogating how western intellectuals are implicated in the production of the " 'concrete' subject[s] of oppression" (Spivak, 1993:87). Spivak takes as her focus the works of Foucault and Deleuze, in which she detects not the disappearance of the "knowing Subject", but instead, "the encroachment of the unacknowledged subject of the West", what she terms "a subject that presides by disavowal" (1993:87). For, as her analysis shows, the questions of who it is that speaks and writes, and what the conditions of agency and domination are that conspire to produce the author as "knowing Subject", are left unmarked. For Spivak this omission is bound to the absence of engagement with the question of the subaltern and failure to examine the ways in which the Subject is constituted through the Other. Spivak terms this unacknowledged constitutive role of the Other "assimilation". "For those of us who feel that the 'subject' has a history and that the task of the first world subject of knowledge in our historical moment is to resist and critique 'recognition' of the third world through 'assimilation', this specificity is crucial" (88). "Assimilation" here refers to the reduction of subaltern subjectivity to the Other, that which can only be thought in relation to the production of the Subject and from the position of the Subject. It is the claim to the possibility of knowing this Other as a subject within and through the schema of western knowledge production that Spivak contests. Like Derrida she argues that it is only through acknowledging the relation between the inaccessible and the interpretable, that which can be analysed and that which resists, confounds and exceeds interpretation, that the postcolonial intellectual "can attempt to displace their own production"(89).

To render thought or the thinking subject transparent or invisible seems, by contrast, to hide the relentless recognition of the Other by assimilation. It is in the interest of such cautions that Derrida does not invoke 'letting the other(s) speak for himself' but rather invokes an 'appeal' to or 'call' to the 'quite other'(tout-autre as

opposed to a self-consolidating other), of rendering delirious that interior voice that is the voice of the other in us'. (Spivak, 1993:89)

Derrida's careful insistence on the otherness of the Other is a way of recognising the existence of the subjectivity of the Other, that which cannot be incorporated or, in Spivak's terms, assimilated.⁹⁵ To recognise the otherness of another as that which cannot be assimilated is to attend to the silences within discourse, to both what has been made unspeakable and to how what is spoken contains the unspoken. At the same time Derrida's conception draws attention to how the voice of the other is also an "interior voice", a voice mediated by the process of listening and interpretation. Derrida recognises the voice of the other as constitutive of the subject and the subject as constituting the voice of the other and does not seek to disavow this relation. This analysis approaches the philosophy of Emmanuel Levinas and of feminist philosophers Adriana Cavarero and Judith Butler, who have elaborated how the subject is always constituted in relation to another.⁹⁶

Spivak argues that when a voice is attributed to the subaltern "subject" what emerges is not the voice of a Subject but that of the authentic Other. As the pre-subjective object through which the subject comes to be formed, the subaltern does not have access to the realm of speech. If the human is constituted in relation to the non-human, and entry into the symbolic, to language, is what marks the human, systematic exclusion from the symbolic produces the non-human. The subaltern cannot speak because the subaltern is not a subject.

Reporting on, or better still, participating in, antisexist work among women of color or women in class oppression in the First World or Third World is undeniably on the agenda. We should also welcome all the information retrieval in these silenced areas that is taking place in anthropology, political science, history and sociology. Yet the assumption and construction of a consciousness or subject sustains such work and will, in the long run, cohere with the work of imperialist subject-constitution, mingling epistemic violence with the advancement of learning and civilization. And the subaltern woman will be as mute as ever. (Spivak, 1993:90)

The closing words of "Can the Subaltern Speak?" draw attention to the urgency in questioning "the unquestioned muting of the subaltern woman even within the anti-

⁹⁵ See for instance, Derrida (1976:191).

⁹⁶ See Levinas (1996), Cavarero (2000), Butler, (1997).

imperialist project of subaltern studies". Spivak writes: "The subaltern cannot speak. There is no virtue in global laundry lists with 'woman' as a pious item. Representation has not withered away. The female intellectual as intellectual has a circumscribed task which she must not disown with a flourish." For her, "the subaltern cannot speak" precisely because as the "the lost figure of the colonised" found by western theory, the subaltern circulates as a figure of transparency.

Spivak's analysis of subjectivity, representation and the production of the Other in "Can the Subaltern Speak?" troubles any reading of testimony as a discourse of truth. Her work draws attention to the critical question of how power conditions the entry of the black female body into the sphere of representation. In the analysis that follows I consider a series of images made by black South African women of their own bodies and point to the complexity that has marked their entry into the public sphere. I argue that besides the significance these portraits hold for the women who made them, they have been interpreted variously as representative of people living with HIV and AIDS in South Africa, as maps that provide a way to navigate the social and bio-medical aspects of life of the women who made them and of poor people living with AIDS generally, and as sites of truth through which the subject of the body can be made known. The images have also been cast as spectacle, reproductions of which have become fetishised commodities that can be bought and sold. Once they became objects for consumption these images also became sites of contest with different stake-holders claiming rights of ownership and the right to profit from their exhibition and sale. I read these portraits also as bodies of loss, as images that gesture towards what we cannot see, what cannot be told because of the violence that attends the entry of the black female body into the realm of representation.

In my reading of these images I briefly consider the social context in which these images were created in order both to draw attention to what is at stake for HIV-positive black women in representing their own bodies, and to draw attention to the courage such representations demand. I then focus on the images themselves, and discuss the complex life-narratives that these images "speak." The power of these "speaking bodies" lies in their insistence on the recognition of the human in the HIV-positive body. In the last section of the chapter I read these self-portraits in relation to photographic self-portraits

by women artists in the west to argue that the bodies of black women continue to be identified as sites of authenticity. In conclusion I point to the work of emerging black South African women artists who are beginning to contest the proscriptions that for so long have governed the representation of black female bodies.

Claiming the body: black women, sexuality and HIV and AIDS

In her essay, "Toward a Genealogy of Black Female Sexuality," Evelyn Hammonds argues that a "politics of silence" and "commodification of Otherness" have overdetermined the attempts of black women to represent their own sexuality (1997:175, 178). She argues that while black female sexuality has been the site of intense scrutiny, at the same time it has been made unspeakable for black women themselves. Hammonds suggests that the material effects of the unspeakability of black female sexuality can be clearly seen in the AIDS epidemic, in which the needs and experiences of black women have not been recognised:

The position of black women in this epidemic was dire from the beginning and worsens with each passing day. Silence, erasure, and the use of images of immoral sexuality abound in narratives about the experiences of black women with AIDS. Their voices are not heard in discussions of AIDS, while intimate details of their lives are exposed to justify their victimization. In the "war of representation" that is being waged through this epidemic, black women are the victims that are the "other" of the "other," the deviants of the deviants, irrespective of their sexual identities or practices. The representation of black women's sexuality in narratives about AIDS continues to demonstrate the disciplinary practices of the state against black women. The presence of disease is now used to justify denial of welfare benefits, treatment, and some of the basic rights of citizenship for black women and their children. (Hammonds, 1997:179)

Though Hammonds refers here to the position of black women in the United States, a similar argument can be made with respect to South Africa where, of the approximately six million people living with HIV and AIDS, more than half are women. While the rights of women have been officially recognised by the South African Constitution, the vulnerability of women to infection with HIV is an indicator of the precarious place they continue to occupy within the emerging social order.

Stigma and discrimination affect all people living with HIV and AIDS in South Africa, but for women an HIV diagnosis often serves to compound their marginalisation and vulnerability to violence and abuse. To cite but a few examples: in 1998, a woman named Gugu Dlamini was beaten to death in KwaMashu, KwaZulu Natal by members of her community who claimed that she was “degrading her neighbourhood” when she disclosed her HIV-positive status on local radio.⁹⁷ Four suspects were arrested for her murder but were released due to lack of evidence. Gugu Dlamini’s family were afraid to testify in court because they too had received death threats.⁹⁸ A young school teacher named Mpho Motloun was murdered in Meadowlands, Soweto in August 2000. On her body was a note that read “HIV-positive AIDS”. According to police, Motloun’s husband killed her and her mother, shot her father who was admitted to hospital in a critical condition, and then killed himself.⁹⁹ In December 2003, Lorna Mlofane – a member of the Treatment Action Campaign – was raped and then beaten to death in Khayelitsha in the Western Cape after she told the men who raped her that she was HIV-positive.¹⁰⁰

What all three of these murders highlight is the paradoxical position of many women in South Africa: they are subject to violence and rape, which increases their risk of HIV infection, and then they are punished by means of violence and rape because they are infected with HIV. While not all HIV-positive women in South Africa suffer violent physical abuse, the context in which they find themselves is one of systemic violence: a context characterised by poverty, stigma, and a lack of access to medical treatment and care. As the murders cited above indicate, women’s bodies are cast as both threatening and contagious in contemporary South Africa – a framing that supports Hammonds’ contention that the bodies of black women have been identified as sites of degeneracy and disease, and that such stereotypes about black female sexuality have proliferated in the context of the HIV and AIDS epidemic (1997:172,179). To disclose one’s HIV-positive status in such circumstances is to put at considerable risk one’s psychological and physical well being. At the same time, disrupting the “politics of silence” is crucial if

⁹⁷ See Kortjaas and Msomi (1998).

⁹⁸ “Dlamini’s ‘afraid to testify in court”, *Dispatch Online*, Friday, January 12, 2001.

⁹⁹ “AIDS test sparks family killing”, *Online Mail and Guardian*, 23 August 2000.

¹⁰⁰ “Men in Court for rape and murder of Cape AIDS activist”, *Mail and Guardian*, 12 January 2004.

the struggles of HIV-positive women are to be recognised. The images I discuss in the next section challenge those regimes of representation that render the experiences of black HIV-positive women invisible.

“An art of the body in resistance”

In *Inventing AIDS*, Cindy Patton describes the ways in which the experiences of people living with HIV and AIDS in the early years of the epidemic were swallowed up by the discursive networks in which they were enmeshed; have been “captured by science, the media, the politicians” (Patton, 1990:131). In such a climate, she argues, it was not surprising that “[t]he only remaining form of speaking was that which fell between the legitimated discourses, something approaching the discourse of art, but *an art of the body in resistance*” (1990:131, my emphasis). The question of how to speak the experience of living with HIV and AIDS remains a critical one in contemporary South Africa. In a context where individual lives have been overshadowed by the highly politicised debate about access to anti-retroviral treatment, one might well ask what “an art of the body in resistance” can speak that the more “legitimated” discourses cannot. The paintings that form the focus of the remainder of this paper foreground the effects of HIV and AIDS on the individual bodies of thirteen HIV-positive women living in Khayelitsha, an informal settlement outside of the city of Cape Town. The images were created as part of a collaborative art and narrative therapy project I worked on over the course of two years.¹⁰¹ Women from two support groups run by *Médecins Sans Frontières* in Khayelitsha took part in a project to draw attention to how access to anti-retroviral therapy affected their lives. These women formed a collective called the Bambanani Women’s Group and created life-size images of their bodies. In these images artistic depictions of scars, wounds, birthmarks, infected organs, skin disorders, broken hearts, pregnant bellies and personal perceptions of HIV tell the stories of their lives. These are

¹⁰¹ The full series of thirteen body images and stories based on interviews conducted by my colleague, Jonathan Morgan, and I, have been published as *Long Life: Positive HIV Stories* (Morgan et.al., 2003). Copies of the recordings of the interviews I conducted with members of the Bambanani Women’s Group are housed at the Centre for Popular Memory at the University of Cape Town.

indisputably individual stories, each one as unique as fingerprints, each one as singular as the body whose story the image tells. At the same time, these highly personal and personalised narratives show how bodily experience is always also an experience of the world – of the intimate intersections of the life of the body and the socio-political context in which that body is situated. The paintings transgress the silences imposed on HIV-positive bodies and serve as visible markers of the forms of injustice to which HIV-positive women are subject. These “bodies in resistance” “speak out”, to and against those who would silence them. At the same time, the question of how what they speak can be interpreted and what is made of what it is that they are thought to have said, perpetually returns.

Produced over the course of several workshops that focussed on how the body holds life stories, the resulting paintings are rich and multi-layered – suggesting that working through and with bodily memories provides a particularly powerful entry point into the narrative of a person’s life. These images create a visual language, a kind of “biological symbolism” that reveals how embodied experience is mediated by the intertwining of the corporeal and the imaginary. This powerful symbolic shorthand is evident in Nomawethu’s image that shows her broken heart surrounded by flames (see *Figure 1*).¹⁰² She explained the image in this way:

Now you see I put that heart. You see there are flames there. The red colour. My heart was broken. It was 1998 in June when I found out that my sister was died and killed herself. She drank some paraffin spirits and threw a match and catch alight then she died in Jooste [hospital]. I saw her there in hospital. Her mouth was gone and her breasts. She did try to talk to me and say you must look after my child then she died. I can’t forget that. It was because her husband was with another woman. He died last year of this HIV illness. I was angry and sad when she died because she support my family. She was the only one to give us a bread and I was so sad because she left a seven year old girl who we look after now. It broke my heart. I was crying from 1998 June till December 1999.¹⁰³

Nomawethu’s anatomically correct “broken heart” is a testament to the way in which psychological trauma is experienced in and through the body. Like Noloyiso’s carefully rendered lungs, which she depicts filled with water surrounded by a storm raging inside

¹⁰² I have made use of only the first names of the members of the Bambanani Women’s Group as some of the participants have not publicly disclosed their HIV status.

¹⁰³ Interview with Nomawethu, Khayelitsha 2002.

her body, Nomawethu's image fuses the symbolic and the literal, the physical and the psychic. This fusion was facilitated by the portrait-making process itself which provided an external body to serve as a screen onto which the inner life of the body could be projected. At the same time, this external body – in its dual capacity as the boundary of the self and the place where the world and the self meet – becomes, in these paintings, the site where the boundary between the inside and the outside of the body dissolves. This fluidity between the inside and the outside, between the world and self, is also to be found in the way that each mark on the body leads to the story of how that body came to be marked, and in the way that the story of each person told through her body incorporates the bodies and stories of others.

For many of the women, the story of their bodies is bound to the stories of their children and their images contain representations of their children's bodies. For example, one of the central images in many of the paintings is that of the unborn foetus. This representation of the foetus living within the centre of the body affirms the body as a site that generates and produces life, and counters the idea of the HIV-positive body as the locus of death. Of the thirteen women in the collective, ten were mothers and several of the women chose to depict themselves as pregnant. In Ncedeka's painting the over-sized figure of a baby is shown superimposed over her body (*Figure 7*). Both inside and outside of Ncedeka's body, this figure represents her baby who died of AIDS at three months old. The larger-than-life-sized body of Ncedeka's daughter conveys the enormity of the impact of her death on her mother and the place she continues to occupy in Ncedeka's memory. Ncedeka's image illustrates how she continues to experience the trauma of the loss of her child at the level of the body; her baby hovers above her like a phantom limb.

Indeed, what the markings on Ncedeka's painting of her body and all the other women's bodily paintings illustrate is how the body, rather than being immune to the outside, is intrinsically connected to the world in which bodies move. HIV infection is a sign of the sociality of bodies, of the life of the body in the world with others. The stories that these images of bodies tell expose the ways in which bodies act and interact, and the ways in which the bodies of women in particular are often violently acted upon. In this light, what is striking about these images is not so much what is there, but what gets left

out. Conspicuously absent from these paintings are sexual partners, husbands, lovers and rapists; the infection of the body through the body of another is only represented in these paintings through the presence of HIV itself. In the absence of these ghostly male bodies, aspects of the violence to which these women's bodies have been made subject remain invisible, and their lives as a result can only be partially understood. It is thus necessary to read with care the stories that are linked to each incision, wound and broken heart; only in reading the paintings in this way can the violence that these women have encountered be understood.

These portraits clearly convey that the effects of infection with HIV reach beyond the body. While illness is revealed as only one aspect of each person's life, the portraits do indicate how the experience of being ill radically transforms how people perceive their own bodies. In particular, the images made by those who have been extremely sick show how overwhelming the appearance of the symptoms of AIDS can be. For example, Nondumiso's depiction of the presence of the virus all over her skin effectively conveys her sense of having been physically disfigured (*Figure 3*). Moreover, in significantly magnifying the virus that covers her body, she indicates that she perceives her entire body to be marked by HIV and AIDS. It is interesting to consider the extent to which the virus has entered both the body and the consciousness of each person, depending on the stage of infection they have experienced. The images made by Noloyiso, Bongiwe and Nondumiso, all of whom had been extremely sick, contrast with the images made by those women who had not yet developed the symptoms of AIDS. In the images made by those who were relatively healthy, the virus is depicted as affecting only a small part of their bodies or is shown outside of the bounds of their bodies. For Thozama, a woman who had not yet become ill, the virus is depicted as a fire that has not yet begun to consume her. She shows herself hovering above flames that burn just beneath her feet (*Figure 6*). For Bongiwe, the person she was when she was severely ill and before she began to take anti-retroviral medication is still inside her body. In contrast to the images made by those women who have had babies and who depict their pregnant bodies, Bongiwe's painting is of her body pregnant with her own sick, smaller self. In the interview I conducted with her she described her image in this way:

This small person inside my stomach: it's me. This picture shows me when I started using ARVs. I was small and so tiny. I was weighing 46 kilograms. It was March this year. Then I started using ARVs and I gained a lot of weight. I have improved a lot. I am weighing 58 kilograms now. So this big body around the small body is me now. When I look at that small person there I feel so sad. But now, I feel happy but at first I was so sad. I thought of many things, that I might die. Anything might happen to me. I was scared at that time because I was losing a lot of weight. That was in March, not so long ago. Now we're in July. It was quick that I got better. Very quick.¹⁰⁴

Bongiwe's self-portrait within a self-portrait, conveying as it does the tiny person she literally became as the virus caused her body to physically waste away, also shows that she perceived herself at this stage in her life as helpless and small (*Figure 5*). The emaciated body that was hers' prior to gaining access to treatment has not been swallowed up by time and forgotten, but is shown as living on inside the larger figure of her healthy self.

Like Bongiwe, Noloyiso had been extremely sick with tuberculosis. She imagines the virus as a storm inside her body, complete with a bolt of lightening tearing across her stomach (*Figure 4*). Her image of raindrops fills the entire middle section of her body and conveys how she felt her body to be completely overwhelmed by her illness. As for Nondumiso, her depiction of the virus's lurid flowering over her skin is not a literal depiction, but one that effectively conveys the trauma she experienced as her skin changed colour. "I feel like going underground", she told me when I asked her how she felt about the ways in which HIV had affected her body.¹⁰⁵

In general, the tendency of these women to depict the presence of the virus both in and on their bodies in ways that render it highly visible can be read as indicating their acute awareness of the stigma attached to HIV and AIDS in South Africa. If these women symbolise HIV through the thorough coding of the body as visibly HIV-positive, it is not only because they have experienced physical symptoms that affected every part of them; it is also their way of making manifest the social symptoms that equally affect them –

¹⁰⁴ Interview with Bongiwe, Khayelitsha, 2002.

¹⁰⁵ Interview with Nondumiso, Khayelitsha, 2002.

symptoms like widespread discrimination and the creation of a climate of fear which make living with AIDS a psychologically, as well as physically, harrowing experience.

In other words, these are images in which the vulnerability of the body at all levels is exposed. In these images the surface of the body has been peeled away, those layers of skin and blood and bone that make one body discrete from another lifted off to reveal the individual meanings of the person who lives that body. In each case, the body is not a surface but an endless depth. These stories are not simply told from the outside in, nor is the inside of the body exteriorised. Rather, the divisions between the outside and inside of the body no longer hold. The body is not the envelope inside of which the narrative "I" is enclosed; the self is the body and the story told is an embodied story. Because of the ways in which these stories are told they do not allow the reader to travel along the surface but draw us in, beneath the skin. There is something transgressive about this practice, this telling which does not close the reader out, which makes the body of the reader porous to the telling itself. For as prevention campaign messages perpetually reiterate, HIV-positive bodies are bodies whose bounds we must not, in any event, cross. The body portraits discussed here refuse such restrictions. The stories of lives that they tell are told not only *through* bodies, but are embodied stories that are re-embodied by those who read them. This, then, is the scandal of HIV-positive bodies that speak: their speaking is the means for the dissolution between the body that speaks and the body that listens. To bear witness to these bodies is to be affected by them: it is to identify *with* – to associate inseparably with – rather than to identify *as* – to name and to distance. These are images that radically disrupt the forms of representation that determine how people living with HIV and AIDS are perceived in that they draw the viewer into the space of the HIV-positive body. These paintings make visible what is invisible; they depict internal organs, living, dead and unborn children, traumatic experiences, loss, sexual violence and HIV itself. As such, they are acts of resistance against the regimes of erasure that seek to make the lives and bodies of people living with HIV and AIDS in South Africa invisible. The women whose bodies are depicted in these images stand exposed in the face of a society, indeed a global community, which largely ignores and thereby condemns them. The courage necessary to make and to display these images in this context should not be underestimated. In many of these images the arms of the

person depicted are raised: a position that can be read as openness but which is equally a sign of defencelessness – the position of a person being arrested, a position that arrests. Either way, it is a position that exposes the vulnerability of the body, one that does not conceal or defend the body but opens the body to scrutiny. The intention of these bodies is to be seen and to face them is discomfiting in that they lead to a series of questions about power and injustice that cannot be easily resolved.

The images created by these women are powerful instances of Maud Ellmann's conception of how the body "is itself a text, the living dossier of its discontents, for the injustices of power are encoded in the savage hieroglyphics of its sufferings" (Ellmann, 1993:17). The women who created these images have laid bare their inner lives and their most intimate embodied experiences in order that their rights and the rights of others in similar circumstances might be recognised. To some degree they have succeeded in securing those rights: reproductions of their portraits have been purchased by the Constitutional Court in South Africa and are part of a permanent public exhibit. The presence of these images of HIV-positive bodies at the symbolic centre of the South African justice system is an important gesture in a context where the rights of people living with HIV and AIDS have been so often overlooked. Yet in spite of the power of these images and the recognition of the plight of people living with HIV and AIDS that their visibility signifies, the women who made them continue to occupy a space of extreme vulnerability to the violence, both individual and systemic, that continues to characterise life in South Africa in the time of AIDS. Such violence also conditions the entry of these subjects into the sphere of representation and places limits on how they can be seen.

Refusing Transparency

“a vigilance precisely against too great a claim for transparency”

Spivak¹⁰⁶

In her essay “The ‘Eternal Return’: Self-Portrait Photography as a Technology of Embodiment”, Amelia Jones reads photographic self-portraits by artists who engage in “an exaggerated mode of performative self-imaging” (Jones, 2002: 948). Jones considers the work of contemporary American photographic artists, Cindy Sherman, Lyle Ashton Harris, Hannah Wilke and Laura Aguilar to “open the question of how subjectivity is established and how meaning is made in relation to *all* representations of the human body” (2002:949). She argues that images like Cindy Sherman’s performative self-portraits, in which Sherman figures enacting a subject that both is and is not herself, destabilise both “the conception of the self-portrait and the very notion of the subject” (947). Jones defines the terms “portrait” and “self-portrait” in the following way:

In the portrait image of any kind, a subject is apparently revealed and documented. In the self-portrait, this subject is the artist herself or himself, and the promise of the artwork to deliver the artist in some capacity to the viewer, a promise central to our attraction to the images, is seemingly fulfilled (Jones, 2002:951).

In the case of the images Jones reads, however, the notion that the image is a replication of, and incontestably attached to, the real, is subverted. “Through an exaggerated performativity, which makes it clear that we can never ‘know’ the subject behind or in the image, these works expose the apparently seamless conflation of intentionality with meaningful visible appearance in the self-portrait as an illusion” (2002:951). The images that form the focus of Jones’ analysis provide a stark contrast to the images that have provided the focus for this chapter. Juxtaposing these images and the ways in which they have been received, throws the distinctions that are thought to exist between western subjects and their marginalised others into sharp relief.

¹⁰⁶ Spivak (1993:89)

I want to suggest that the popular appeal of the self-portraits I have discussed in this chapter is connected to how these images have been cast as sites of authenticity, points of access to the real. These portraits, considered suitable for display at the Constitutional Court and at galleries across Europe and North America, are premised on the idea that their subjects can be known, not only by the artists themselves, but also by those who view them.

In the previous chapter I considered how narrative has increasingly come to be attached to photographic images that represent people living with HIV and AIDS in Africa as a way to secure photography's claim to representing the truth of its subjects. Post-colonial and feminist theorists, human rights activists, anthropologists, and others have drawn attention to the persistence of a colonial politics of display in representations of marginalised peoples and the related silencing of their experiences. I argued that in response to this critique, photographers, artists, ethnographers and anthropologists have set about restoring the "native's voice" through documenting their testimonies. As Rey Chow notes, the "problem with the reinvention of subjectivity is that it tries to combat the politics of the image, a politics that is conducted on surfaces, by a politics of depths, hidden truths, and inner voices" (1993:29). In *Writing Diaspora*, Chow revisits some of the questions raised by Spivak in "Can the Subaltern Speak?" "Is there a way of 'finding' the native without simply ignoring the image, or substituting a 'correct' image of the ethnic specimen for an 'incorrect' one, or giving the native a 'true' voice 'behind' her 'false' image?" Chow asks (1993:29).

How could we deal with the native in an age when there is no possibility of avoiding the reduction/abstraction of the native as image? How can we write about the native by not ignoring the defiled, degraded image that is an inerasable part of her status – i.e., by not resorting to the idealist belief that everything would be alright if the inner truth of the native is restored because the inner truth would lead to the 'correct' image? [...] How would we write this space in such a way as to refuse the facile turn of sanctifying the defiled image with pieties and thus enriching ourselves precisely with what can be called the surplus value of the oppressed, a surplus value that results from *exchanging* the defiled image for something more noble? (Chow, 1993:30)

But where does this leave the black woman artist engaged in representing her own experiences of embodiment? In an essay focusing on the work of two emerging black

women photographers engaged in the production of images that contest the objectification of black women's bodies Desiree Lewis writes,

Deconstructing textual and visual misrepresentations of black women's sexuality now constitutes a significant trajectory in scholarship by or about black women (see Gilman, 1985; Giddings, 1992; Carby, 1987 and Abrahams, 1997). But relatively little scholarly production deals with how black women have viewed their bodies, especially with how black women have sought to re-envisage their bodies and sexuality. (Lewis, 2005:11-12)

In her analysis of the images of Zanele Muholi and Ingrid Masondo, Lewis shows how the work of contemporary black women artists issues a decisive challenge to the regimes of power that have determined how black women are represented. Muholi's photographic works depicting the lives of black lesbians is exemplary in this regard. Her work radically reconfigures what has been considered "good and proper" subjects for black women artists, in the same moment exposing how such prohibitions continue to condition the representation of black female sexuality.¹⁰⁷

Like Muholi, contemporary South African artist Bernie Searle takes the body as her primary site of interrogation. Searle has used her own body extensively in performance installation and video works through which she stages her engagement with notions of identity, memory, fixity and flux.¹⁰⁸ In her 2004 video work "Float" Searle set her own body afloat in the Mediterranean Sea between Morocco and Spain. Searle's evocative work suggests that if there is a truth to be found in the body it is that the body is overlaid by history and that the body exceeds history. This truth is not situated in the depths of the body but can be known only through an interrogation of the surface, the history that floats on the body, the history within which the body floats. Searle's work unmoors the body from singular definition and offers a mode of resistance to the production of black women as sites of authenticity and transparent subjectivity.

While such contestations of the restrictions placed on depictions of black women's desire, sexuality and experiences of embodiment may be read as cause for celebration, the subject matter of many of these works decidedly complicates such a

¹⁰⁷ Muholi was born in 1972 and is a gender and sexual rights activist and photographer. See www.michaelstevenson.com/contemporary/exhibitions/muholi/muholi.htm where a selection of her works can be viewed online.

¹⁰⁸ Originally trained as a sculptor, Searle (b.1964) is now a photographer and installation artist. On Searle's work see Sobopha (2005) and Klopper (2006).

position. Muholi's works depicting hate-crimes perpetrated against black lesbians testify to the ongoing violence that attends the expression of black female sexuality and desire in South Africa. The importance of her work lies precisely in foregrounding how this violence continues to determine how black women subjects are represented.

As I have sought to show in this chapter, representations of the bodies of black HIV-positive women in South Africa cannot be read as transparent. To take such representations as points of access to the truth of the subjects they represent is to disavow the relations of power that continue to determine how such images appear and how they can be read. In another sense however, the self-portraits of HIV-positive women I have read here, and my own interpretations of them, participate in what Spivak has termed "strategic essentialism". While these images can be read as aesthetic objects, at the same time, and like the testimony offered at the Truth and Reconciliation Commission victim's hearings, they constitute a claim to recognition by the law. What is at stake in their production, circulation and interpretation for the women who made these portraits is the recognition of their claim to the right to life and to biological citizenship.



Figure 1



Figure 2



Figure 3



Figure 4



Figure 5



Figure 6



Figure 7

Chapter Six

Mourning the Present

We have shown the unmistakable tendency to push death aside, to eliminate it from life.

Sigmund Freud¹⁰⁹

In this dissertation I have focussed primarily on visual material, tracing the appearance and simultaneous disappearance of the bodies of people living with HIV and AIDS within discourse. I have analysed a diverse range of images and texts which portray living bodies cast as dead. I have sought to follow the trajectory of the HIV-positive body through a particular kind of political order and discursive field. Within this order, which corresponds with Foucault's notion of the "bio-political", two kinds of embodied subjects emerge. Those constituted in relation to the state as living citizen-subjects and those consigned to death-in-life. As I have argued throughout this dissertation, these bodies marked for death disrupt the symbolic order of the bio-political and define its limits. In this final chapter I show how the disappearance of the dead bodies of those who have died of AIDS makes visible the public disavowal of loss. The chapter focuses on how the material bodies of the dead weigh on the living and demand recognition.

I begin with Auschwitz survivor Charlotte Delbo's reworking of an account told to her of the massacre by the Germans of all the men of the village of Kalavrita in Greece in 1943. I cite it at length because of what it suggests about how to think about mourning and mass death.

When all the women arrived above the ravine, they came to a halt and stayed standing there. Without moving. Mute. What was to be done? What were they to do? For the dead of the ordinary sort one knows what to do. But for these ... this enormous pile of dead. This huge heap.
[...]

¹⁰⁹ "Timely Reflections on War and Death", first published in 1915 as "*Zeitgemasses Uber Krieg und Tod*", see Freud (2005:183).

Then someone said: "First we must ready them for burial. After that we will have to bury them."

Laying out a body for burial, everyone knows about that.

As for the burying itself ...

The gravedigger was there, dead with the others.

And what gravedigger has ever buried thirteen hundred dead all at once? Who could dig thirteen hundred graves in a single day, particularly in our stony soil?

And the coffins? The carpenter was there, dead with the others.

What carpenter could build thirteen hundred coffins in a day? He'd never have the materials for thirteen hundred coffins. What carpenter ever stocks enough wood for thirteen hundred coffins all at once?

The carpenter, the smith, the farrier, the miller, the wheelwright, the woodcutter, they were all there, dead with the others.

And where would you bury them? There wasn't room enough in the cemetery for thirteen hundred graves. A cemetery is something that grows little by little over the years.

We couldn't just leave them there.

We didn't know how to bury them.

And it was as though they were dying a second time, by being there dead,

deprived of the respects that are due to the dead.

Each dead man has the right to a coffin. But the carpenter was there, dead, and so was the blacksmith for the nails and the handles.

Each dead man has the right to a grave dug for him. But the gravedigger was there, and so were all those who would have helped dig.

Each dead man has the right to a funeral mass. But the priest was there too, among the dead.

Doesn't each dead man have the right to a final resting-place, a resting-place with a tombstone bearing his name? But the stonecutter was there as well, among the dead.

All the artisans were dead. To whom would the boys be apprenticed when they came of age?

Then one of the women said: "We must bury all of them together."

"Bury them where? You can't dig a hole in the stones at the bottom of the ravine."

"We must bury them all together, they died all together."

"Without coffins, without anything?"

"Without coffins, with our hands."

Charlotte Delbo¹¹⁰

"For the dead of the ordinary sort one knows what to do", Delbo writes, but what can be made of thirteen hundred deaths on a single day? And what of the same number dead, as is the case in South Africa now, each day of the year? Delbo's description of how

¹¹⁰ Delbo (1990)

traditional burial practices are rendered impossible (the carpenter, blacksmith, priest, gravedigger and stonecutter are all dead) reveals how the ritual practices of mourning are intimately related to the constitution of community. The process of mourning is one of remembering the past through marking the relation between the living and the dead. In this sense mourning is also futural; the ways in which we mourn, the ritual practices of mourning, play a central part in imagining life beyond the dead, the after-life of community that is formed through the relation between the living and the dead. In Delbo's account the loss of those individuals who would have made possible the burying of the dead signifies the loss of the "ordinary sort" of death, the loss of loss itself.

Indeed, in Southern Africa today "ordinary death" increasingly belongs to the past and if our capacity to mourn has limits, they are surely being tested now. Such limits take material form through the bodies of the dead, so many, that they cannot be contained in existing graveyards in South Africa. Newspapers report that as mortality rises so burial practices are shifting; more than one person is assigned to each grave, and these graves themselves are being recycled. Cenotaphs are to be constructed, mausoleums where the remains of hundreds, perhaps thousands, can be housed at once. We are quite literally overwhelmed by the presence of the dead and what is lost is simultaneously that which is all too present.

And yet the question of how to accomplish the work of mourning in a time of unending loss is a suspended question in South African politics and life. It is a question that we have not been asking for much too long because the lives of people living with HIV and AIDS have not been recognised as lives and their deaths thus could not be mourned as deaths. It is a question that was overshadowed by the Truth and Reconciliation Commission and the process of mourning the losses incurred under apartheid. It is a question that has been marginalised, perhaps necessarily, by the struggle to assert the right to life and to treatment for people living with HIV and AIDS. And yet no matter how we forestall it or how helpless we feel in the face of it, it is a question that recurs with each untimely death that is made publicly ungrievable.

It is the problem of mourning that forms the central focus of this final chapter, wherein I consider what it means that so many deaths have been allowed to pass all but

unmarked in South Africa in the time of AIDS.¹¹¹ Through the juxtaposition of two accounts that deal with the mass deaths of young people in South Africa, the first written during apartheid, the second in the age of epidemic, I argue for the necessity of mourning, for a culture that collectively grieves. This is not because I understand melancholia (as some do) to be a productive or redemptive state, but because of the fundamental relation that exists between mourning and recognition.¹¹² It is through the lives of others that we are constituted; in mourning their deaths we acknowledge their lives as well as how we are indebted to them for our being, so much so that their deaths are experienced as a loss of ourselves. Failing to mourn the death of the other is not only to allow their death to go unmarked, nor is it only to fail to recognize the value of their life. It is also to disavow the constitutive relation between the self and the other; the recognition that their life and death is bound to my own.

In the second section of the chapter I read a series of portraits of people living with HIV and AIDS by contemporary South African artist, Diane Victor to argue for keeping open the possibilities of movement between the living and the dead; the vanished and the visible; the present and the past. I draw on the writings of philosopher Emmanuel Levinas, who argues for the recognition of the interrelatedness of being and for an ethical response to the corporeal vulnerability of the other.

The concluding section takes as its focus the life narrative of Pindiwe, an HIV-positive woman I interviewed in 2002. I argue that the position she occupies outside of community, the position of many people living with HIV and AIDS, severely impairs her ability to accomplish the work of mourning. I understand mourning, in this time saturated by loss, not only to be the process of grieving for the dead but as ritualised forms of the recognition of all we are losing, and all that is lost. Recognising the value of what is lost is also to be cognisant, and reverent, of what remains.

¹¹¹ On mourning and the HIV and AIDS epidemic see Crimp (1989; 2003).

¹¹² Slavoj Žižek provides an excellent critique of the prescribed “rehabilitation of melancholy” within academia today. See Žižek (2000). On the relation between mourning and recognition see Butler (1999; 2004, 2004(b)) and Eng and Kazanjian (2003).

The Political is Personal

Read in conjunction, *The Diary of Maria Tholo* and Sindiwe Magona's short story "Leave-taking" foreground the continuities and disjuncture between life, death and mourning in South Africa during apartheid and in the present. *The Diary of Maria Tholo* is an account of life in the townships just outside of Cape Town in 1976, the year of the student uprisings against the apartheid state and a time of intense violence and mass death.¹¹³ Read alongside Magona's short-story about a mother who has lost three of her children to AIDS and who is isolated in her grief, Tholo's description of politicized mourning casts the disavowal of the losses of AIDS in a particularly clear light. Under apartheid politics usurped personal grief and mourning was instrumentalised – used to mobilize communities in support of the struggle against the state. Practices of collective grieving meant that few spaces remained open for personal expressions of grief. At the same time such practices served to affirm not only the connection between the living and the dead but also to strengthen the bonds between those who mourned. As Tholo's account of the funeral of the first student to be killed in the riots in Langa in 1976 reveals, public mourning was banned by the apartheid state but effectively prescribed by the community. Tholo relates how the state's prohibition on public mourning led to the practice of political funerals:

Yesterday was a day of funerals. The first one was that of the Mosi boy. Now because he was the first student to be killed in the riots the police were worried that there would be trouble at the funeral so they told Mrs. Mosi that only very close relatives could attend, not more than 20 people. I hear that they threatened her that if she allowed a crowd she would be endorsed out of Cape Town because she is here illegally. I don't know why she is not living with the father. He is from Kingwilliamstown but he came here for the funeral. Now with Africans twenty people is impossible. Who can decide who is a close relative? (Hermer and Tholo, 1980:23)

The "day of funerals" Tholo describes marked the beginning of the intensification of the armed struggle and the declaration of the States of Emergency, during which time the

¹¹³ Tholo narrated her story to Carol Hermer in a series of interviews conducted over the course of 1976. The text was transcribed by Hermer. The book includes Hermer's commentary on the events Tholo describes and provides additional contextual information. The book also contains photographs of students protesting in Cape Town, policemen in Guguletu, and a series of images by South African photographer Ronnie Levitan of living conditions in the township of Langa.

state implemented martial law. Between 1976 and 1990, when political prisoners began to be released from South African jails, thousands of people were held in detention without trial, tortured and killed. It is interesting to note that in 1976 however, Tholo deemphasizes the political reasons why it was “impossible” for just twenty people to attend the funeral of Xolile Mosi. “Now with Africans twenty people is impossible. Who can decide who is a close relative?” she writes, indicating that the loss of a person’s life affects not only the immediate family but the extended family and the community as a whole (1980:23).

She goes on to relate how, in spite of being forbidden to attend the funeral, the school children of the townships disguised their uniforms beneath their parent’s work clothes and marched to the cemetery. All the people who lived on the road that led to the graveyard came out of their houses to watch and all of them were crying. As the children reached the gate of the graveyard the police appeared and threatened to shoot them if they advanced:

The children didn’t stop. One of the boys called out, ‘They say they don’t shoot school children. Let them prove it today.’ The policemen crowded together to stop them entering the gate.

And then as if a switch had been pulled the girls started wailing. You know how Africans can scream. ‘Wah, wah, wah. It’s not a dog that’s being buried. We want to see our comrade. We want to see our fellow-student.’ The people around took up the chorus and the next moment it was just pandemonium with everybody screaming ‘Yes! Yes! Yes!’ and then the teargas shot out. (Hermer and Tholo, 1980:25)

In claiming their right to bury their fellow student, the children of the township assert not only the value of Mosi’s life, his humanness, but also their own. In this time the slogan “an injury to one is an injury to all” characterised the resistance movement and the lives and deaths of all those united in the struggle against apartheid were recognised as interrelated. At the same time, public displays of solidarity became a requirement – those who failed to mourn in the appropriate ways risked violent punishment. Tholo recounts how, on Christmas day in 1976 in the townships around Cape Town, the students requested that everyone wear black for a week to show that they were in a state of mourning. In Langa and Guguletu the students forbade anyone from attending church and insisted that everyone go to the graveyard instead.

“ ‘But who are we burying?’” Tholo asks her young neighbour, a high-school student in Langa. “ ‘Auntie, it’s best for you to go and find out for yourself. Those who aren’t there will be noticed. And let me tell you, I wouldn’t go to church because when we come from the graveyard woe unto those we find there.’” (1980:165).

On her way to the graveyard with her elderly mother Tholo encounters two of her friends returning to their homes. They tell her that “the whole town’s there” to “tidy up the graves” (168).

It was one thing hearing it. Arriving was still a shock. I have never seen so many people. I hadn’t understood what they meant about tidying up the graves. I thought perhaps we had to clean the graveyard or something. But what it was was that we had to mould the graves, make the mounds of earth on top, because these graves were flat. They weren’t like the usual ones, rounded on top. These graves were separate, in three long rows of about fifty in each line. There were so many I couldn’t count any more.

[...]

Unknown graves. I was too scared to openly ask questions, but you start feeling your way and people start talking. These graves, we heard, were riot deaths who were buried by the police in the night. Some of the comrades used to come and watch. The people of Section 4 said they used to see the police coming along with big plastic bags, those rubbish bags, and bury them there. Some of the comrades dug them up to find already decomposed bodies, sometimes more than one in a bag. So, it was said, these were the graves of the unknown people who were just shot at random during the riots.

Well, you couldn’t know whether there were also coloureds buried there, or even convicts. But it was still terrible to think that so many people could be buried like that without the parents or people or relatives or anyone knowing.

At the beginning of each line of graves there was a man with a spade with earth on it. You took a handful and put it on the grave. Now all day from six o’clock in the morning people had been coming to put a handful on each grave. You could tell how many people must have been there, from all the townships, Nyanga, Langa, Guguletu and all, because these mounds were growing.

I counted two out of all those graves that had a flower on them, a lousy little plastic flower, where the family had been to the police station and had found out the number of the grave. All over people were crying. There were those who had lost their relatives or who still didn’t know where their children were. They couldn’t help but cry to think that maybe it was their child on whose grave they were throwing earth, but which one, which one? There were so many.

All the time there was this low singing, the sad hum of the freedom songs, and all the time more people, coming, coming. I am used to going to funerals but it had never felt so heavy, people milling around singing, others crying quietly. (1980: 168-9)

At the site of these unmarked graves the community claims these dead as their own. Without knowing whose remains were interred there, the mourners grieve for other people's children, "coloureds", "or even convicts", as if they were their own. The graveyard becomes a site of transcendence; collective loss overcomes individualization, overcomes even prejudice. Mourning becomes the law.¹¹⁴

The incident Tholo describes can be read as a communal work of mourning, one which secures the social bond in a time of injustice, violence and mistrust. At the same time Tholo's own response to the ritual is telling. While she identifies with the families of those who have been killed she also reveals that she participates in the ritual because it is politically expedient, and even necessary, for her to do so. Her public display of solidarity through grief is not equivalent to private grief, a grief that may be shared but that is not harnessed to political ends.

In South Africa today accomplishing the work of mourning is no less complicated, nor is it less political, than it was in the time that Tholo describes. For the silences that surround the deaths of people who die of AIDS are not signs of the normalization of processes of mourning. The absence of communal mourning practices for people who have died of AIDS do not signify the opening up of spaces for the expression of a more private form of grief. Instead, as I have sought to show throughout this work, people living with HIV and AIDS have been positioned outside of the realms within which their lives would be recognised as lives and their deaths considered grievable deaths. This too is political and should be recognised as such. What is lost, as Magona's "Leave-taking" so powerfully conveys, is the affirmation of, and possibility for, community that emerges through the recognition of loss as communal, grief as collective.

Magona's story begins by describing a funeral that takes place in the same cemetery in Guguletu where Maria Tholo participated in communal mourning rites almost thirty years before. At the graveside of her daughter, the third of her five children to die of AIDS, Nontando publicly renounces her faith: "God – I hate you!" she screams, before collapsing under the weight of her grief (Magona, 2004:124). With this curse Nontando rejects not only the God that has forsaken her but also the church and the

¹¹⁴ I draw this phrase from the title of Gillian Rose's book. See Rose (1996).

community that “had offered not the slightest reprieve or consolation” to her while her children were ill (2004:134). Magona draws attention to how the stigmatisation of people living with HIV and AIDS redoubles Nontando’s grief. At the end of the story Nontando descends into a deep melancholic state, not, Magona implies, because of the magnitude of the losses she has had to bear, but because she has had to face them alone.

When the Mfundisikazi, the priest’s wife, asks Nontando what she thinks the women of the church could possibly do about the epidemic, Nontando replies, “Why what we always do when death visits any of our member’s families” (134). But the Mfundisikazi is quick to remind her that a death from AIDS is not like any other death. “I thought we could also start talking among ourselves about *esi sifo sabantwana* [the disease of the children] and perhaps warn those not yet infected,” Nontando suggests.

“*Dadewethu Nkosini*, my sister in the Lord,” replied Mrs Seko, wrinkling her nose and curling her lips in derision and exasperation. When she saw Nontando would not so easily be sent away, she resorted to church canon. She would put the matter before *amagosa* (the church elders), at the next vestry meeting. Nontando knew full well that had Mfundisikazi wanted any of this to happen, she would have found a way to make it happen. Referring it to *amagosa* was killing it. She was not surprised when *amagosa* were up in arms that the request had been made at all.

“How can a true Christian suggest we talk dirty in church?” one wanted to know. (Magona, 2004:134)

In despair “as a last resort” (135), Nontando approaches Mfundisi Seko, whom, “she’d heard, *she knew* [...] had buried several young people who had died of AIDS related diseases” (135). The minister offers nothing but platitudes. When Nontando tells her husband, Thando, that she has spoken to the leaders of the church about their children and has disclosed the fact that their daughter is HIV-positive, he is outraged.

“Is it not enough that the whole world knows of our disgrace, that Luthando has *lo gawulayo*, this chopper of a disease?”

“AIDS?”

“Stop that!” Thando screamed. “I don’t want to hear that dirty word in this house.”

“It lives here.”

“It wouldn’t if the decision were up to me.”

That stole Nontando’s tongue. Silence. She could not believe what she’d just heard her husband say. (2004:136)

For Thando, affirming the presence of AIDS by speaking of it brings it into existence. If no-one utters the word “AIDS”, he implies, the more quickly it will disappear. And

indeed, the bleak picture Magona portrays of the premature deaths of HIV-positive young people bears this out. No-one in the story speaks of the existence of anti-retroviral therapy. All Nontando's children rapidly develop severe opportunistic infections and their early deaths are represented as inevitable. Thami, Nontando's daughter, is pregnant when she is diagnosed HIV-positive but decides to have an abortion. Her decision is portrayed as the only option open to her. In spite of the fact that Thami's husband is a doctor, an oncologist at the state hospital where Thami is admitted when she becomes sick, no mention is made of medical interventions that might ward off her death. Magona's own silence about the contested issue of access to treatment, perhaps a sign of her lack of knowledge about anti-retroviral therapy, points to one of the most harmful effects of the injunction not to speak about HIV and AIDS. The social death people living with HIV and AIDS endure hastens their physical deaths.

AIDS, as Nontando puts it, "lives here". Thando's response, however, like that of so many South Africans for whom AIDS remains unspeakable, reveals his attitude that the sooner people living with HIV and AIDS are dead and buried, the better. But as Nontando's melancholic suffering indicates, it is not possible to let go of the dead, to accomplish the work of mourning, if we have not been permitted to recognize their lives. After the death of her daughter, throughout the seven day wake, Nontando refuses to eat or to speak. "It was not normal, some said. Not natural, said others" (141). Magona's story makes clear however, that what is not "normal" or "natural" is the failure of the community to mourn the losses that have befallen them. In order to grieve the deaths of her children Nontando aligns herself with the dead and in her identification with them, is cast out of the community of the living.

The Weight of Ashes

In her memoir *Hospital Time*, Amy Hoffman writes of how she imagined her responsibility for her friend, Michael Rielgle, sick with AIDS and to whom she was the primary caregiver, would come to an end once he died. "I dreamed of the day when I would have no contact with Mike's remains, his possessions or his associates. Of course it didn't happen that way. I ended up with the ashes. In ashes begin more responsibilities.

They were heavy.” (Hoffman, 1997:85) Hoffman’s text reveals the ambivalence of her desire – at once to rid herself of Mike and not to let him go. Ultimately, Hoffman refuses to disavow the pain of losing her friend. In a section entitled “Calling the Names” Hoffman writes of how at gay pride marches and activist meetings in the United States she would participate in a ritual recitation of names of lovers, friends and family members who have died of AIDS. “The accretion of names reveals an image: a glimpsed freeze-frame of our lives hollowed out by loss” (1997:91). She writes of how the list of names goes on and on:

Will this calling of the names never end? It could, in fact, go on for days – although the MC halts it after a while. There is other business to attend to. We have not gathered only to call out names. Must we not make peace? Must we not move on? But my teeth are chattering, my body humming. I can’t stop feeling the reverberations.... (Hoffman, 1997:91)

Hospital Time ends with Hoffman’s answer to these questions and shows that for her, accomplishing the work of mourning is not only an impossibility, but that even if it were possible, it is not what she would choose.

In “Kaddish”, the concluding section of the book, Hoffman describes the Jewish prayer for the dead as “a prayer of reconciliation” and “Of acceptance” (149), and also as a prayer that she will not say. Hoffman’s book testifies to the importance of recognising the interrelatedness of life and death, what Judith Butler has termed “the powers of mourning”.¹¹⁵ *Hospital Time* is a meditation on how the multiple losses of AIDS necessitate an engagement with mourning in and for the present. Mourning the present is to recognize not only what we have lost, but also what we are losing in failing to recognize the relation between the living and the dead.

In South Africa artists and writers have begun to engage with the disavowal of mourning that has attended the deaths of people living with HIV and AIDS. Visual artist Diane Victor’s series of portraits of people living with HIV and AIDS is perhaps the most evocative and powerful in this regard.¹¹⁶ Victor’s “Smoke Portraits”, 36 images made from photographs she took of patients at St Raphael HIV and AIDS day clinic in

¹¹⁵ Judith Butler, *Precarious Life: The Powers of Mourning and Violence* (2004).

¹¹⁶ Victor was born in 1964. She is best known as a printmaker.

Grahamstown on a single day in 2004, are rendered with candle smoke on paper.¹¹⁷

Victor's work was shown alongside Churchill Madikida's "Status", a multi-media installation work that also took the losses of AIDS as its subject, at the Michael Stevenson Contemporary Art Gallery in Cape Town from October to December 2005. She has subsequently created a series of images of missing children using the same medium. Besides their technical virtuosity, Victor's images, vulnerable to the slightest touch, are remarkable for their ability to convey the fragility of embodiment and of life itself (see *Figures 1-4*). In her statement prepared for the exhibition Victor points to how the medium itself is central to the meaning of the images.

The portraits are made with the deposits of carbon from candle smoke on white paper. They are exceedingly fragile and can be easily damaged, disintegrating with physical contact as the carbon soot is dislodged from the paper. I was interested in the extremely fragile nature of these human lives and of all human life, attempting to translate this fragility into portraits made from a medium as impermanent as smoke itself.¹¹⁸

Part of the power of the work lies in the simple statement displayed alongside the images, which serves to make the overwhelming effects of the epidemic and the losses this entails painfully clear: "These images are derived from photographs of people living with HIV and AIDS waiting at a clinic in Grahamstown and were all taken on a single day." While each image can be read on its own as an individual study, the work is intended to be displayed (and sold) as a group. Viewed together the images create a powerful "portrait" of HIV and AIDS in South Africa and, while Victor did not determine who attended the clinic on the day she photographed the patients, her subjects represent a cross-section of those affected by HIV and AIDS. And yet the performative force of "Smoke Portraits" does not consist only in the beautiful, disturbing series of faces that work against the defacement of people living with HIV and AIDS, but in the questions the appearance of these disappearing forms seem to ask. What are the effects of all these disappearances, these mass deaths that have fundamentally altered the order of life and death in so many parts of the world and yet have passed by, unmarked, invisible, disavowed? What does it

¹¹⁷ For a brief overview of Victor's work see Smith (2005).

¹¹⁸ <http://www.michaelstevenson.com/contemporary/exhibitions/victor/smoke.htm>

mean that these losses have been made publicly ungrievable? In raising these questions and in creating a space for those who view them to “face” them, Victor’s work points to how we can begin to recognize our loss.

I read these images as works of mourning. Unlike photographs which attest to the impossible desire to capture and fix the real through reproduction, Victor’s “Smoke Portraits” do not participate in this logic of permanence.¹¹⁹ Instead, in their vulnerability to time they more closely resemble “real” bodies and powerfully evoke the fragility of human life. Although the medium demanded that the artist work quickly, and the effect of the smoke with which they were created means that the images appear smudgy, the faces depicted laden with soot, every portrait attends to the idiosyncrasies of the individual subject depicted. These are at once incredibly detailed images (like photographs, they are clearly of specific people each with their own unique features), and images of disintegration and disappearance. These images carry echoes of other times of mass death: the Nazi death camps and the “ovens”, all the bones and teeth and hair transformed into objects of use or burnt away; the atomic bombs detonated in Nagasaki and Hiroshima and the ghostly figures of those close to the epicenter of the explosions that appeared on the walls, black shadows burnt into the architecture, a terrifying remainder.¹²⁰

Victor’s medium captures a sense of those she depicts hovering between life and death, a series of ghostly faces simultaneously present and absent.

In “Mourning and Melancholia” Freud asserts a relation between these two states, understanding “profound mourning” and melancholia to be virtually indistinguishable. “It is really only because we know so well how to explain it [the mourner’s single-minded “devotion” to mourning] that this attitude does not seem to us pathological.” (1917, 2005: 244) For Freud, mourning is not pathological because it ends.

It is well worth notice that, although mourning involves grave departures from the normal attitude to life, it never occurs to us to regard it as a pathological condition

¹¹⁹ See Peggy Phelan’s fascinating discussion of how, counter to the argument I am making here, “Taken together, the works of Benjamin, Barthes and Woodman suggest that photography might be the best medium we have for responding to the ongoing temporality of the work of mourning” (Phelan, 2002:979).

¹²⁰ See Delbo (1995) and Friedrich (1996) on the Nazi death camps. For an evocative analysis of the apocalyptic effects of the atomic bombs in Hiroshima and Nagasaki and the production of *hibakusha* or living-dead in Japan in relation to the position of people living with HIV and AIDS, see Haver (1996). I am grateful to Stuart Murray for drawing my attention to Haver’s work.

and to refer it to medical treatment. We rely on it being overcome after a certain lapse of time, and we look upon any interference with it as useless or even harmful. (Freud, 2005:243-244)

In their transience, and against Freud, “Smoke Portraits” define the process of mourning in the time of AIDS as necessarily perpetual. While Freud does not pursue what it would mean to “interfere” with mourning or what harm such interference might cause in his essay, Albert Camus’ novel *The Plague* can be read as an extended meditation on the effects of loss that seem to exceed our ability to mourn and that are made publicly ungrievable. In Oran, the town in which Camus’ novel is set, premature death is not only commonplace but inevitable, and there is no place for grief. Camus connects the erosion of the ability of the townspeople of Oran to mourn the losses they have suffered to the loss of “every trace of a critical spirit” (1947, 1968:151).

None of us was capable any longer of an exalted emotion; all had trite, monotonous feelings. ‘It’s high time it stopped,’ people would say, because in time of calamity the obvious thing is to desire its end, and, in fact, they wanted it to end. But, when making such remarks, we felt none of the passionate yearning or fierce resentment of the early phase; we merely voiced one of the few clear ideas that lingered in the twilight of our minds. The furious revolt of the first weeks had given place to a vast despondency, not to be taken for resignation, though it was none the less a sort of passive and provisional acquiescence. (Camus, 1968:149)

The “plague” Camus describes has been read as a metaphor for the German occupation of France in the 1940’s and can be read as an engagement with the difficulties involved in remaining “awake” to the suffering of others.¹²¹ It is also a powerful critique of a world “peopled with sleepwalkers” for whom the conditions of plague – injustice, mass death, the circumscription of grief – become normal and to which they acquiesce (1968:151). “For there is no denying that the plague had gradually killed off in all of us the faculty not of love only but even of friendship. Naturally enough, since love asks something of the future, and nothing was left us but a series of present moments” (1968:150). For Camus, grief is a form of waking, a reminder of life beyond or outside the amnesiac conditions of plague.

When the somnolence of the townspeople of Oran is interrupted, what flashes up briefly before them is “the mournful visage of their love” (151). Victor’s “Smoke

¹²¹ See Felman and Laub (1992:93-119).

Portraits” perform a similar task, making visible what Levinas terms an “asymmetry of intersubjectivity” – the vulnerability of the other and the recognition of what the loss of the other implies for the self.

Victor’s portraits are images of faces in the ordinary sense and in the Levinasian sense – “Face as the very mortality of the other man” (Levinas, 1998:186).

But in this *facing* of the face, in this mortality – a summons and a demand that concerns the *I*, that concerns me. As if the invisible death which the face of the other faces were *my* business, as if that death “had to do with me.” The death of the other man implicates and challenges me, as if, through its indifference, the *I* became the accomplice to, and had to answer for, this death of the other and not let him die alone. It is precisely in this reminder of the responsibility of the *I* by the face that summons it, that demands it, that claims it, that the other is my fellow-man. (Levinas, 1998:186)

The Melancholy of the Public Sphere¹²²

Between January and March 2002 I documented the stories of forty HIV-positive people who participated in the Memory Box/Positive Lives Project at the South African National Gallery in Cape Town. All the participants were members of the Red Cross support group in Khayelitsha and just two of the forty people had access to anti-retroviral therapy through *Médecins Sans Frontières*. Each person made a memory box over the course of four days and then narrated their story to me. I transcribed their words and printed them for display alongside their boxes in the gallery. I began each interview in the same way. Together with the person who had made the box, I would examine the images and text they had created and then ask them where they would like to begin. The excerpt below is drawn from the interview I conducted with Pindiwe, a woman who chose to begin by talking about the image she had made of herself in her coffin:

Interviewer [hereafter “I”]: Where should we start?

Pindiwe [hereafter “P”]: This side.

I: Pindiwe, what is the story that is here?

P: I was thinking when I’m dead. When I’m in the coffin.

I: So who is this person here?

P: Me.

I: And where is this place that you’ve drawn.

¹²² Judith Butler, *Antigone’s Claim* (2000:81)

P: The coffin is underground.
 I: And where is this graveyard?
 P: At my home in Transkei.
 I: Which place is that where you are from?
 P: Tsolo.
 I: Where is it near to?
 P: Near Umtata.
 I: Is that where you were born and is that also where you were growing up when you were a small child?
 P: Yes.
 I: And so is that the place you want to return to when you die?
 P: Yes.
 I: and how did it feel for you to be making this picture that you've put here?
 P: I was very sad and worried.
 I: And then after you finished the picture, did you feel any different?
 P: I was also very worried and sad.
 I: And what is it that you feel sad and worried about?
 P: My child.
 I: How many children do you have?
 P: Five children.
 I: And how old are they?
 P: First one is born in 1983, 1984, 1987, 1993 and this one also.
 I: When was this one born?
 P: 2000, June.
 I: And where are all your children living now?
 P: They are at their father's place.
 I: and where is that place?
 P: One is at Tsolo, the other one is in Umtata, the other one is here in Cape Town.
 I: And so is this the only child you are staying together with?
 P: Yes.
 I: And who do you live with now?
 P: I am staying alone.
 I: Just you with your child?
 P: Yes.
 I: And the father of your children?
 P: The father ran away, I don't know where he is now. Maybe he is around Cape Town, I don't know.
 I: So does that also worry you? About who will support your children?
 P: Yes.
 I: Is that is what is worrying you for after you die?
 P: Yes.
 I: Is there anybody else in your family that can support you?
 P: No. I don't have.
 I: When did you find out that you were HIV-positive?
 P: June 2000.
 I: And your baby?

P: Negative.

I: Did you take AZT or nevirapine?

P: AZT. Yes I did.

I: Where was that that you got the AZT?

P: Mowbray Maternity hospital.

I: And how did you feel when you were giving birth to your child, were you worried when you knew that you were HIV-positive?

P: Yes I was very worried and I wanted to commit suicide.

I: When you found out you were pregnant or after you gave birth?

P: After I heard about my status.

I: Because were you diagnosed when you were pregnant?

P: Yes when I was pregnant.

I: and so after that you say that you felt that you wanted to commit suicide. So were you very depressed in that time, or how did you feel?

P: Yes I was very depressed because I never think about that for myself that I will get HIV.

I: And was there anyone to support you in that time when you were pregnant?

P: No, I was having nobody.

I: You are a very strong woman.

Do you have any other stories on this box that you want to share.

P: I have drawn my home. I was thinking of my mother.

She passed away.

I: Is this your mother or who is this here?

P: My brother.

I: And these are the trees that are growing there by your house?

P: Yes.

I: This is in Tsolo?

P: Yes.

I: And can you tell us what you wrote here?

P: I hate HIV. It's a devil.

I: Did you draw this ambulance here?

P: I will be in ambulance when I become sick.

I: So that hasn't happened yet? Or have you been very sick yet?

P: No, it hasn't happened yet.

I: But it's what you are feeling worried about?

P: Yes.

I: Do you think that if you become sick you will begin to take anti-retroviral treatment?

P: Yes I want.

I: Because you know, I think maybe you have seen some people, they are taking those pills and they are coming right.

P: Yes, I've seen the example of Lamla [a member of the support group who had access to treatment through MSF].

I: Those medicines can help you very much and they can help you to live for a very long time.

Did you know that? But it doesn't help to think about it, or...

P: Yes I want those drugs.

I: Does it help you in any way if you think that you can get them?

P: Yes it can help me.

I: But what I mean is, does it make you feel less worried?

P: Yes, I'm thinking about those drugs. But the problem is now that I am staying alone. Then I said to myself, "Who is going to look after me when I am sick?" because those drugs are for those people who have got somebody who are living with them, that they are offering those drugs. That is the problem that I am... Yes I think I can get those drugs but I don't have somebody that is staying with me now.

I was drawing my father there who is late also. This is also my home.

I: Is there anybody who can support you?

P: No. There is nobody.

And my boyfriend is just left me. He is staying at Makaya.

I: Is he the father of this child?

P: Yes.

I: and is he the father of any of your other children as well?

P: Only that one.

I: How long ago did he leave?

P: Since December.

I: And before that were you living there together?

P: Yes.

I: And why did he decide to leave?

P: There's no reason why he left us. Unless when he's drunk he just shouted at me then just go out and be with his friends. I think the problem is that when he is drunk I went to the police station and lay a charge. I think that is what made him run away.

I: Did your boyfriend become abusive when he was drunk?

P: Yes, yes he's aggressive and my right ear is not working properly.

I: So he would hit you when he was drunk?

P: Yes.

I: How did you find it to tell your story on this box?

P: I feel alright.

I: Did it help you to be able to tell your story or not really?

P: Yes it helped me to tell my story.

I: How did it help?

P: The problem is that it is hard to tell my family, like my brothers and sisters about the status. So it is hard inside.

I: Are you saying that you feel quite alone?

P: Yes.

I: Do you think that if you spoke to some of the people in your family maybe some of them might be able to support you?

P: No. Because there is that stigma that when you are HIV-positive you are sleeping around a lot.

I: Do you know for sure that that is their way of thinking?

P: Yes.

I: Because you've heard them speak about it before, or why?

P: I've heard them from another girl who was sick, they said "she's got AIDS" and that girl never told them that she's HIV-positive.

I: Have you felt different physically since you found out you were HIV-positive?
 P: No, I don't feel any difference. There's no difference.
 I: Have you been sick at all or have you lost weight?
 P: I never lose weight because I was born with this weight. I never get sick.
 I: Is there anything else you would like to say or is there any other story you would like to share?

Silence.

I: Does it help you to have a child? Because I'm always thinking about this because I don't have a child myself. So I was thinking, is it good to have a child or sometimes does it just make you so tired?
 P: No, it is good to have a child.
 Ok, I have also got this pain here in my back.
 I: What is it coming from, from carrying your baby maybe?
 P: I am thinking of that beads work that I'm doing. Maybe it is part of that beads work.
 I: Pindiwe, *Nkosi kakhule*, thank you for sharing your story with me.

Pindiwe's narrative cuts through the platitudes and piety that constitute public discourse on HIV and AIDS: "My friend with AIDS is still my friend", "Love to Be There", "HIV loves skin on skin", "I know my status do you?"¹²³ Which of these speaks to Pindiwe's melancholia? What will keep her from suicide? How can we tell her that she is not alone in her isolation? Unable to mourn the loss of her own present, and from there to move on to thinking of a future, Pindiwe is fixed in a state of melancholia. I read Pindiwe's depression and her desire for death as a symptom of the prohibition on mourning the losses of AIDS.

It is interesting to consider the relation between publicly ungrievable losses in South Africa in relation to prohibitions against public mourning in other places. Writing in the aftermath of violence that has characterized the response of the United States to the attacks on the World Trade Centre on September 11 2001, Judith Butler considers how "certain forms of grief become nationally recognized and amplified, whereas other losses become unthinkable and ungrievable" (2004:xiv). For her, the disavowal of mourning leads to a war without end.

I argue that a national melancholia, understood as a disavowed mourning, follows upon the public erasure from public representations of the names, images, and narratives of those the US has killed. On the other hand, the US's own losses are

¹²³ These phrases have all appeared as part of public awareness campaigns, most of them on billboards, in South Africa.

consecrated in public obituaries that constitute so many acts of nation-building. Some lives are grievable, and others are not; the differential allocation of grievability that decides what kind of subject is and must be grieved, and which kind of subject must not, operates to produce and maintain certain exclusionary conceptions of who is normatively human: what counts as a livable life and a grievable death? (Butler, 2004:xiv)

Butler's diagnosis of "national melancholia" can well be applied to South Africa where the losses of AIDS have been publicly disavowed. As I have sought to show throughout this dissertation, the struggle that faces us lies not only in remembering those who have died but in recognising the living. For how do we mark the deaths of those whose lives have been excluded from the realms within which lives are understood as lives? Their deaths, as Butler argues, are not just poorly marked but unmarkable.

Indeed, Giorgio Agamben has remarked that we live increasingly in a time in which populations without full citizenship exist within states; their ontological status as legal beings is suspended. These are not lives that are being genocidally destroyed, but neither are they being entered into the life of the legitimate community in which standards of recognition permit for an attainment of humanness. How are we to understand this realm, what Hannah Arendt described as the "shadowy realm," which haunts the public sphere, which is precluded from the public constitution of the human, but which is human in an apparently catachrestic sense of that term? Indeed, how are we to grasp this dilemma of language that emerges when "human" takes on that doubled sense, the normative one based on radical exclusion and the one that emerges in the sphere of the excluded, not negated, not dead, perhaps slowly dying, yes, surely dying from a lack of recognition, dying, indeed, from the premature circumscription of the norms by which recognition as human can be conferred, a recognition without which the human cannot come into being but must remain on the far side of being, as what does not quite qualify as that which is and can be? Is this not a melancholy of the public sphere? (Butler, 2000:81)

This suspended status, this position outside of or beyond the law, comes about through the interaction between multiple forms and practices of social exclusion and the lack of recognition by the law. I have argued that people living with HIV and AIDS occupy a place between life and death, – what Agamben refers to as "zones of abandonment". To have been abandoned implies the disavowal of sameness, the withdrawal of recognition. To be abandoned thus implies having once been included and points to a primary and prior state of relation, and thus to the possibility of community. Spaces of inclusion are always haunted by the possibility of the return of the oppressed.



Figure 1



Figure 2



Figure 3



Figure 4

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